Family Experiences: The Impact of Family Structure and Autism Spectrum Disorder on Social Outcomes

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Dedication

For Derek, and Ingrid, and Teddy

I hope to make you three as proud and as happy as you make me, every day. I love you.

Abstract

In the nearly two decades since tracking began, prevalence of autism spectrum disorder (ASD) in children has continued to rise. In order to best serve families, is important to understand the unique experiences of families who have a child with ASD. Drawing on family stress adaptation theory, and primarily on the Double ABCX Model of Adjustment, factors which contribute to a family's positive adaptation are identified and analyzed. This study investigates the relationships among families with children with ASD and a number of indicators of socioeconomic status, including public benefit usage, parental education, and income. The study also characterizes the family unit, seeking to understand the distribution of family structures in which children with ASD reside. The study sample included 22,697 families with children ages 3 to 17 surveyed in the 2014 and 2015 National Health Interview Survey (NHIS). A number of logistic regression models were run to test associations. The findings indicate that families with ASD are having different experiences than families who have children with no diagnosis of ASD on a number of outcomes. Findings include a two year pooled prevalence estimate of children with ASD of 2.25%. Additionally, population estimates of family structures for children with ASD were calculated. The effects of autism on family structure revealed children with ASD had lower odds of living in a two parent household and higher odds of living with a single mother compared to children without ASD. The effects of ASD and family structure on a number of outcomes were analyzed. Compared to two parent households with a child without an ASD diagnosis, single and two parent households with a child with ASD had higher odds of government benefit usage, higher odds of household income under $50,000, and no difference in highest parental educational

attainment. These results have implications in policy and practice for families with children with autism spectrum disorder.

Keywords: autism spectrum disorder, ASD, socioeconomic status, SES, family structures, National Health Interview Survey, NHIS, disability

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Chapter I: Introduction

According to the Centers for Disease Control and Prevention, estimated prevalence of autism spectrum disorder (ASD) has steadily risen in the United States since tracking of the condition began in 2000 (Christensen, et al., 2016). Accompanying the rise in prevalence of autism spectrum disorder is an increased interest in factors impacting families of children with ASD. While it is known that having a child with ASD results in greater stress to a family in a number of ways, a thorough understanding of family structures, financial impacts, and related socioeconomic factors are largely unknown, or have been represented inconclusively and disparately in the currently available literature.

The purpose of this study is to increase understanding of the experience of families who have children with ASD in a number of important ways using a large national dataset, the National Health Interview Survey (NHIS). In this study, a number of methods are used to understand ASD and the family. First, an autism prevalence estimate using pooled data and sample weights from the 2014 and 2015 NHIS is provided. This estimate uses data from two years, offering a more stable, as well as updated, estimate. Next, population estimates across family structures are generated using NHIS provided sample weights. These population estimates are important as characterizing the types of families which children with ASD reside in is key to understanding family experiences. These estimates also allow for comparisons with the general population. Finally, a series of logistic regression models are used to understand associations between autism, family structure and public benefits and indicators of SES.

Looking at education, income, and an analysis of families' public benefit usage provides useful information for understanding the experiences of families with children with ASD.

Statement of the problem

The prevalence of autism spectrum disorder (ASD) has steadily risen since the Centers for Disease Control and Prevention (CDC) began tracking the condition in 2000. Recent reports describe a prevalence of one in 68 children, or approximately 1.5% of the eight-year-old population (so used as research indicates this is the age by which children with ASD are identified) (Christensen, et al., 2016; Yeargin-Allsopp, et al., 2003). Given the rising prevalence, there is increased attention on autism spectrum disorder. Total funding for autism research, services, training, and monitoring under the National Institutes of Health, the CDC, and the Health Resources and Services Administration is estimated to exceed three billion dollars by 2019 (Autism Speaks, 2014).

Understanding the family experiences of children with ASD is important to understanding the impact of ASD on family outcomes. Despite a focus on ASD at the individual level, less is understood about the family experiences and outcomes related to having a child with ASD. The following chapters will provide a review of the relevant theoretical frameworks that have contributed to understanding ASD within the family unit as well as an examination in to the impact of ASD on a family as described in the research literature. Additionally, an overview of ASD is provided, with relevant information on the impact of recent diagnostic updates.

Statement of Purpose

This study aims to explain how having a child with autism spectrum disorder is associated with a number of family outcomes, including family structure, socioeconomic factors, and demographics. This study uses quantitative data to provide descriptive statistics and is correlational in nature, relying on a series of statistical analyses to describe the relationship between autism spectrum disorder and these domains using National Health Interview Survey (NHIS) data.

Research Questions

This study is designed to answer the following research questions.

1. What is the two year pooled prevalence rate of families with children with ASD?
2. Do family structures of children with ASD differ from the general population?
3. Does having a child with ASD relate to higher odds (likelihood) of specific family structures?
4. What are the effects of ASD and family structure on public benefit usage?
5. What are the effects of ASD and family structure on household income?
6. What are the effects of ASD and family structure on parental educational attainment?

Significance of the study

This study utilizes pooled data from the 2014 and 2015 National Health Interview Survey (NHIS), a respected and nationally representative dataset to provide a deeper understanding of family structures and experiences for those families who have a child with autism spectrum disorder. While literature exists describing the impact of ASD on families, and primarily mothers, in terms of stress levels, there is little else known about the family experience, especially using a large quantitative dataset. This study provides a picture of how autism spectrum disorder and the family come together at a national level, offering a clearer picture than previously available on the associations between having a child with autism and outcomes related to family structures and socioeconomic factors. Certain family structures are more likely to experience a shortage of resources such as economic hardship (Kalil & Ryan, 2010). This study contributes an understanding of different family structures that children with ASD reside in. Indicators of SES are strongly correlated with the health and development of children (Susser, Hopper, & Watson, 1985) and this study offers an understanding of these in relationship to families with children with ASD. Family resources are important to promoting resiliency and healthy adaptation. Families suffering financial hardship who have trouble meeting basic needs such as stable housing, access to medical care, and food, may suffer from negative impacts to marital and parent-child relationships (Conger & Elder, 1995).

This study draws on theories related to recognizing strengths and resiliency in families. Further, the Double ABCX model provides a theoretical framework toward understanding the key factors and process by which adaptation occurs in the family unit. By highlighting challenges and family realities, there is the potential for developing

future interventions appropriately targeted to families, and for understanding policy and programmatic implications for the service delivery system.

Chapter II: Autism Spectrum Disorder

This study concerns families with children with ASD. In order to understand the topic more fully, this chapter provides an overview of autism spectrum disorder, including recent updates to the definition of the diagnosis.

Background on Autism Spectrum Disorder. ASD is a developmental disability that can cause significant challenges in social, communication, and behavioral realms (Centers for Disease Control and Prevention, 2010). ASD is marked by deficits in social interaction, communication, and the presence of restricted, repetitive behaviors. Challenges in social interaction and communication may include deficits in sharing of emotions, interests, and initiating and responding to social interactions. People with ASD may experience challenges engaging in nonverbal communication during social interactions, and difficulties with understanding, developing, and maintaining social relationships. Restricted, repetitive behaviors may include: stereotyped or repetitive motor movements, use of objects, or speech; insistence on sameness, rigid adherence to specific routines or rituals, experiencing difficulty with minor alterations; unusually intense, focused interests; and, either excessive or lacking responsiveness to sensory input or unusual interests in sensory aspects of the environment. ASD symptoms vary based on age, language level, and cognitive development. Symptoms typically present in early childhood, though some children are not recognized until later, when in social situations which exceed their capacities (American Psychiatric Association, 2013).

Autism spectrum disorder is defined by the time of onset, prior to three years of age, deficits or challenges in reciprocal social interaction and communication, and restricted and repetitive behaviors and interests (Centers for Disease Control and

Prevention, 2010). As a spectrum disorder, these traits express diversely across people. Reciprocal social interaction can include lack of social-emotional reciprocity, failure to seek shared enjoyment, and poor use of nonverbal communication. Communication deficits refer to a failure to acquire speech without compensating with other communication methods, using stereotyped speech or echolalia, and difficulties with conversing. Restricted and repetitive behaviors include unusual preoccupations and limited interests, repetitive hand and finger movements, whole body mannerisms, compulsive behaviors and rituals, and preoccupations with parts of objects (such as unusual sensory seeking behaviors) (Centers for Disease Control and Prevention, 2010).

There is no scientific consensus regarding the causation of ASD. Several risk factors have been identified including genes (though no single genetic marker is identified), having a parent or sibling with ASD, other medical conditions including Down syndrome (among others), and ingestion of certain drugs during pregnancy. The median age for diagnosis of ASD is 4 to 5 years of age. Recent data suggests there is typically a gap of two years between developmental concern to diagnosis (Centers for Disease Control and Prevention, 2010). When assessed by a clinician experienced with toddlers with autism, a stable diagnosis may be reliably made; that is, diagnoses made at or before age two tend to remain stable upon follow up at age three and beyond (Rogers, 2001).

Diagnostic changes. The diagnosis for autism spectrum disorder underwent significant changes between the Diagnostic and Statistical Manual (DSM)-IV-TR (2000) and DSM-5 (2013). Previously, Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS), Rett's syndrome, and

Childhood Disintegrative Disorder (CDD) were all grouped under one category of Pervasive Developmental Disorders, and therefore ASD was referred to as autism spectrum disorders. As of DSM-5, published in 2013, the previously separate categories, with the exception of Rett's syndrome, have been subsumed in to one category, reflecting scientific consensus that they are actually a single condition with different levels of severity in the two core domains of "social communication and interaction" and "restricted and repetitive behaviors." Rett's syndrome was dropped due to recent evidence it is a genetic disorder (American Psychiatric Association, 2013).

Background of ASD in the DSM.

Historical definitions of autism. The term "autism spectrum disorders" was first proposed in 1991 based on concerns that Pervasive Developmental Disorder (PDD) resulted in unclear distinctions. Most research to identify distinctive features of Asperger's, autism, and PDD-NOS failed to find any reliable differences across PDD subtypes once IQ or language was controlled. Distinctions among subtypes were inconsistent over time and variable across clinicians (e.g., Frith, 2004; Howlin, 2003; Lord et al., 2011; Macintosh & Dissanayake, 2004; Ozonoff, South, & Miller, 2000; Prior et al., 1998; Snow & Lecavalier, 2011). Furthermore, subtypes had poor predictive validity of child outcomes (Miller & Ozonoff, 2000; Szatmari et al., 2009; Szatmari, Bryson, Boyle, Streiner, & Duku, 2003) and thus were uninformative for treatment planning. While the term was not adopted in the DSM-IV or ICD-10, "autism spectrum disorders" became commonly used (Williams et al., 2008). A review of the history of autism reveals a changing conceptualization of the diagnosis over time, highlighting the

impact the prevailing scientific culture has on how the diagnosis is determined and understood.

Autism was described as early as 1943, classifying children who had previously been described as “emotionally disturbed” or “mentally retarded” (Silverman & Brosco, 2007). In the decades since, changes in the conceptualization of ASD has occurred (Volkmar & McPartland, 2014). Early research focused on autism as a related to childhood psychosis or schizophrenia (Volkmar & McPartland, 2014). This led to many children and families being subjected to misdirected and expensive therapies (Wolff, 2004). By 1979, autism was recognized as distinct from schizophrenia (Wolff, 2004). Two notable lines of research in the 1970s led to autism being look at distinctly from schizophrenia and subsequently being included in the DSM-III in 1980 as standalone diagnosis for the first time. These included a diagnostic model which accounted for early onset along with speech and language difficulties unique from intellectual disability, as well as a focus on rigidity and resistance to change, and a hyper/hyposensitivity to the environment (Volkmar & McPartland, 2014). In addition to focusing on childhood autism, this early definition did not offer flexibility in terms of diagnosis; that is, every criterion had to be met for the condition to be diagnosed.

The DSM-III revised version (DSM-III-R) grouped criteria into three main areas of impairment: reciprocal social interaction, communication, and restricted interests (Volkmar & McPartland, 2014). Of the sixteen criteria, eight had to be met for a diagnosis to be given. While the revised version better accounted for changes in development, it resulted in increasing false positives, partially because it emphasized current examination without inclusion of early history (Volkmar & McPartland, 2014).

Revisions to the diagnosis for the DSM-IV included inclusion of other disorders under the umbrella category of autism, including: Asperger's disorder, Rett's disorder, and Heller's syndrome. In addition to the issue of accurate diagnosing, there was an emphasis on aligning the DSM-IV with International Classification of Disease (ICD) codes (at this time, ICD-9) (Volkmar & McPartland, 2014). The ICD is the standard diagnostic tool for epidemiology, health management and clinical purposes, and is used to monitor incidence and prevalence of health conditions across populations (World Health Organization, 2014).

Work in the 1980s focused on the epidemiology of autism amongst children in special education. This was useful in uncovering that children with autism both with and without co-occurring intellectual disabilities benefit from the same educational and therapeutic models (Wolff, 2004). At the same time, there was attention to Asperger's syndrome, conceptualized as high functioning autism, which brought about an understanding of autism as a spectrum disorder (Wolff, 2004). The DSM-IV included Asperger's disorder.

DSM-5 definition. The DSM-5 introduced significant changes to the categorization and diagnosis of ASD. The major change included the removal of the separate diagnostic labels of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) in favor of one diagnostic label of Autistic Spectrum Disorder (Centers for Disease Control and Prevention, 2014). Further, distinctions within the umbrella term of Autism Spectrum Disorder are made based on severity levels. Severity levels are influenced by the amount of support a person needs due to challenges with social communication, restricted interests, and

repetitive behaviors. Additionally, more symptoms are required to meet criteria for a diagnosis and the symptoms themselves have been reorganized. Instead of separating impairments in Communication and in Social Interaction, these are combined in to one category titled "Social/Communication Deficits." A delay in language development is no longer necessary for a diagnosis. Inclusion of early history has been important in the diagnosis of autism due to the emphasis on early onset as a criterion (prior to age three); DSM-5 requires that symptoms begin in early childhood, but includes the caveat that "symptoms may not be fully manifest until social demands exceed capacity," for example, in later adolescence (American Psychiatric Association, 2013).

Impact of changes to the DSM-5. The decision to eliminate Asperger's disorder from the DSM-5 has been controversial. There are suggestions that under DSM-5, only 60% of people currently meeting criteria for autism under DSM-IV will meet the criteria under DSM-5 (Yang & Bai-Lin, 2011). The changes have been described as "radical" on the one hand, resulting in a loss of services for many people (Fitzgerald, 2012), and on the other hand, as "largely cosmetic" (Tryer & Craddock, 2012). There is evidence that when comparing DSM-IV and DSM-5, those individuals who will not meet the new criteria will have not met enough of criteria in the area of restricted, repetitive behavior and interests, and will therefore miss out on receiving needed supports, especially since they may have marked impairment in verbal communication and still not meet the criteria for diagnosis (Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012). Others have suggested that individuals who meet criteria under DSM-IV will continue to do so under DSM-5 (Volkmar & McPartland, 2014). The impact remains to be seen, and will need to be assessed after the new criteria have been widely implemented by clinicians.

The changes to the DSM-5 reflect an effort to make the diagnosis of Autism Spectrum Disorder more specific, reliable, and valid. Some individuals previously diagnosed with an Autism Spectrum Disorder utilizing the DSM-IV-TR may no longer qualify for services using the DSM-V criteria (Greaves-Lord, et al., 2013). Further, while systems will undoubtedly need to respond to the changes, it is unknown how state, educational, insurance, and other services may respond to and adopt the changes. Research suggests that the effect could be tempered by adaptations of the diagnostic practices and documentation of behaviors to fit the new criteria, and offered support for the reorganization of ASD symptoms as in the DSM-5 (Guthrie, Swineford, Wetherby, & Lord, 2013). Individuals who may have formerly met criteria for one of the conditions no longer present in DSM-5 (such as Pervasive Developmental Disorder-NOS) may be without a diagnostic home. The result is that individuals who were receiving services under and ASD diagnosis may no longer qualify for treatment that may have been beneficial to their symptoms and functioning (Swineford, Thurm, Baird, Wetherby, & Swedo, 2014).

There are also concerns that those individuals who are considered higher functioning who have previously met the criteria for an ASD will no longer do so under the DSM-5. Without a diagnosis, these individuals, it is feared, will also have difficulty accessing services. People who had been diagnosed with Asperger's Disorder or PDD-NOS may be particularly at risk for this outcome (Greaves-Lord, et al., 2013). Females with ASD may also be under-identified, as found in a study examining the sensitivity and specificity of the DSM-5 (Frazier, et al., 2012).

The Autism and Developmental Disabilities Monitoring Network (ADDM, discussed below) surveillance data has been gathered and reported for 2002, 2006, 2008, 2010, and 2012 using case definitions based on the DSM-IV TR diagnostic criteria for the following conditions: Autistic disorder, PDD-NOS, and Asperger Disorder (APA, 2000). The changes due to the implementation of the revised diagnostic criteria in DSM-5 are not yet understood. Indeed, the rising prevalence of ASD that has been observed over time may be due to changes in diagnostic criteria and improved identification methods (Fombonne, 2005). ADDM Network methodology offers an opportunity to apply ASD surveillance case definitions based on both the past and current diagnostic criteria in order to increase understanding of the effect as a result of the changes to the DSM-5 on prevalence and characteristics of ASD.

The revisions have important implications for school psychologists and clinicians responsible for evaluating children with ASD, interpreting results to caregivers, and informing and advising policy makers. Changes to the DSM-5 resulted from decades of research, and future research will be influenced by how ASD is now defined within the DSM-5.

Chapter III: Literature Review

This study aims to characterize the experiences of families with ASD across a number of factors. Knowing the number of children with ASD is important to understanding the scope of the population impacted, and this study provides an updated prevalence estimate. Understanding the family structures of children with ASD contributes to the characterization and limited existing research identifying the experiences of this population. This is important as certain family structures are known to be more vulnerable in terms of resources than others. The theoretical frameworks drawn upon for this study offer explanations for the relationships between resources and adaptation. This study also seeks to expand knowledge on families with a child with ASD and indicators of socioeconomic status and public benefit usage. These, too, are important resources for a family with ASD. This chapter provides a review of the research literature related to these topics, beginning with an understanding of prevalence and ASD, and moving on to understanding families within the context of having a child with ASD. Finally, this chapter explores the relevant theoretical frameworks and models employed in developing this study.

Scope: estimating prevalence of Autism Spectrum Disorder

Grinker, Yeargin-Allsopp, and Boyle (2011) reviewed published research across the world, and found insufficient data to estimate the prevalence of autism outside of North America and Western Europe. The authors point out that, while this may lead one to believe that knowledge of autism does not exist outside of these places, it is rather a product of the history of autism research and researchers, who were both European-American, and whose foundational work continues to be utilized today (such as Leo

Kanner). The authors also point out that despite the lack of epidemiological studies on ASD around the world, awareness, advocacy, education and treatment opportunities have been rapidly advancing. The authors cite the existence of national autism societies in over 100 countries, and the emerging scientific research occurring in parts of Africa, India, several Middle Eastern countries, Mexico, and Venezuela, among others (Grinker, Yeargin-Allsopp, & Boyle, 2011).

Estimating prevalence in the United States.

ADDM methodology. The primary means for estimating prevalence of ASD in the United States is through the CDC's Autism and Developmental Disability Monitoring (ADDM) Network. The ADDM Network is a group of programs funded by CDC to determine the number of people with ASD in multiple communities across the United States, though they are not intended to form a nationally representative sample (Centers for Disease Control and Prevention, 2014). The ADDM Network lists several main goals, including: a) to provide data about prevalence of ASD; b) describe the population of children with ASD; c) compare the identified prevalence of ASD among different groups of children across difference geographic locations nationally; d) identify the changes in the identified prevalence of ASD over time; and, e) to understand the impact of ASD and related conditions in communities across the nation (Centers for Disease Control and Prevention, 2014). The methodology is designed to cast a broad net to identify a subset of children with symptoms of ASD. There are large differences in prevalence across ADDM Network sites. Data are limited to their geographic region. In comparing ADDM Network data, it is most useful to view changes site by site, as diagnostic practices are more likely similar within a region than across the country. In

following prevalence trends, it is important that methods are adhered to over time in order to observe meaningful changes, and the ADDM Network offers a rigorous methodology which can be tracked across surveillance years.

ADDM Network prevalence rates. Prevalence results from the ADDM Network's 2014 report (Centers for Disease Control and Prevention, 2014) are based on 2010 data reported from eleven ADDM Network sites. The overall prevalence rate of ASD was one in 68 children aged 8 years, representing about one percent of children in the United States (in line with estimates from other industrialized nations) (Centers for Disease Control and Prevention, 2014; Rice, et al., 2013). As shown in Figure 1, overall, prevalence rates have increased since tracking began. Estimated prevalence of ASD increased roughly 123% between 2002 and 2010; between 2010 and 2012, prevalence remained about the same (Christensen, et al., 2016).

Figure 1. ADDM Network prevalence estimates

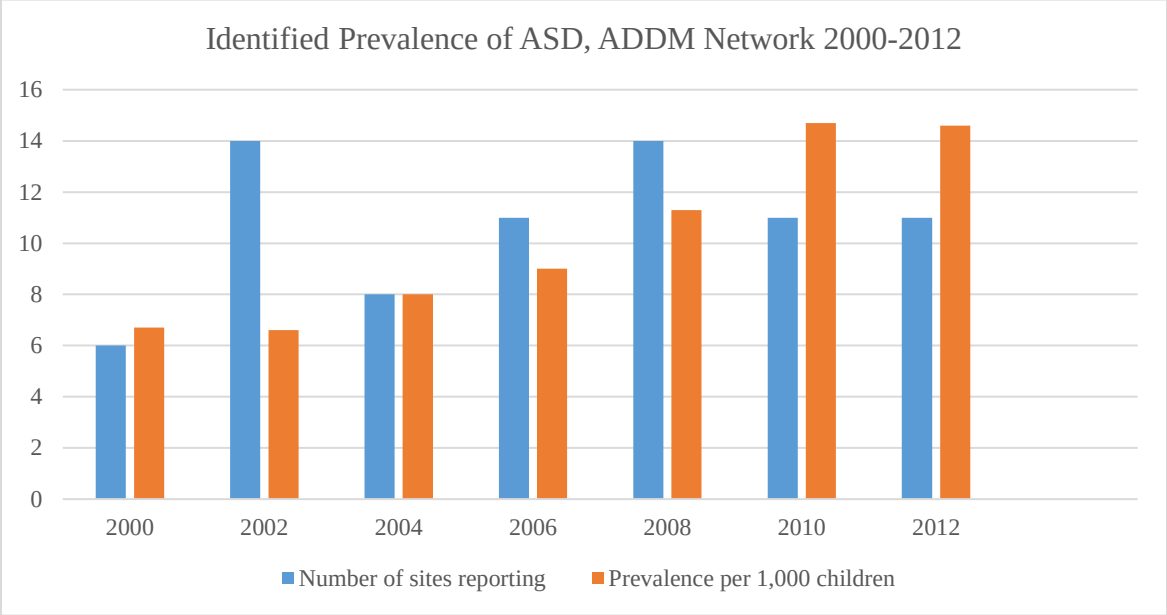


Chart adapted from ADDM Network Morbidity and Mortality Weekly Report (Christensen, et al., 2016).

Prevalence across sites varied, which may be attributed to differences in diagnostic practices, under-identification of ASD symptoms in certain groups, socioeconomic disparities impacting access to services, and regional differences in clinical or school-based practices around identification and services (Christensen, et al., 2016). Further, the report shows that Black and Hispanic children continue to be less likely to be identified with ASD than White children, and that these groups receive developmental evaluations later than White children, highlighting the need for targeted strategies to address barriers to evaluation, diagnosis and connections to services for these families. The report also shows that only 43% of children identified with ASD receive developmental evaluations by age three, suggesting children are not being identified as early as they could be; while there is no evidence of an intervention reducing prevalence of ASD, early treatment has been shown to make a difference in the ability of children to function and participate more fully in their communities (Christensen, et al., 2016).

Other CDC methods for ASD surveillance: The National Health Interview Survey and the National Survey of Children's Health. In addition to the ADDM Network, CDC conducts the National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH). The three systems utilize different sampling strategies and methods to ascertain ASD. While results from each survey or program are not comparable, they are complementary in helping to understand a more comprehensive picture of ASD among children across the nation (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Table 1 offers a comparison of the three methods.

Table 1. Comparison of National Health Interview Survey, Autism and Developmental Disabilities Monitoring Network, and National Survey of Children's Health

	National Health Interview Survey	**Autism and Developmental Disabilities Monitoring Network**	**National Survey of Children's Health**
Year of most recent data set	2015	2012	2011-12
ASD prevalence estimate	22.4 per 1,000 children	14.6 per 1,000 children	20.0 per 1,000 children
Age of target population	3-17 years	8 year olds	6-17 years
Case ascertainment method	Parent-reported survey responses about a lifetime ASD diagnosis	Expert clinicians review medical and education records, applying a surveillance case definition of ASD	Parent-reported survey responses about current ASD diagnosis
Catchment or target population	In a national in-person household survey of the civilian	In 14 communities across the U.S. (contiguous counties/areas in	In a national telephone survey of households with children

	noninstitutionalized population	AL, AZ, AR, CO, FL, GA, MD, MO, NJ, NC, PA, SC, UT, WI)	
Survey sample size	Approximately 13,000	Approximately 360,000	Approximately 95,000
Most recent previous data set	2014	2010	2007

Adapted from: (Zablotsky B. , Black, Maenner, Schieve, & Blumberg, 2015).

While complementary, the ADDM Network also provides additional information on specific characteristics of children with ASD as well as tracking changes in communities and subgroups over time. It is important to note, the NHIS changed the developmental disabilities survey questions from previous years in 2014, including reordering and a new approach to asking about ASD (as described in detail in the Methods section) (Zablotsky B. , Black, Maenner, Schieve, & Blumberg, 2015).

Evaluation of methods to estimate prevalence. Estimating prevalence of autism spectrum disorder is challenging (Rice, et al., 2007; Nonkin Avchen, et al., 2010). Table 2 provides a summary of the primary methodologies used to estimate prevalence and their advantages and disadvantages.

Table 2. Primary methods for estimating autism prevalence

Method	Description	Advantages and disadvantages
Systematic Record Review*	Reviewing health and educational records to identify children with autism behaviors	• Cost-effective way to estimate in large communities • Does not rely on existence of a prior diagnosis or label of ASD • Relies on quality and quantity of information in records
Population Screening and Evaluation	Screening and evaluating all children in a population	• Accuracy • Costly, time-consuming • May reflect a participation bias
Registries	Voluntarily including self or child on a list of people with ASD	• Low cost • Can be time consuming • Only includes individuals with a clear diagnosis and those aware of the registry and willing to be on list
Administrative Data	Reviewing service records from health or educational agencies	• Low cost • Underestimates as not all children with ASD are receiving services

Note, *, denotes ADDM Network method. Chart adapted from: (Centers for Disease Control and Prevention, 2014).

Elsabbagh, Divan, Koh…et al (2012) conducted a review of the various methods to estimate prevalence worldwide. The authors conducted extensive reviews of the

literature for epidemiological reports, primarily searching Medline publications, but also searching region-appropriate, and other search engines in order to be as exhaustive as possible. The authors also reached out to other researchers and clinicians in regions where it was difficult to identify epidemiological reports. This resulted in reviewing over 600 additional studies not typically included in reviews, and from regions that are often under- or unrepresented in such reviews. The researchers found a global median prevalence estimate of 62/10,000 (Elsabbagh, et al., 2012). While prevalence research is growing in locations across the world, the vast majority of prevalence studies have occurred in North America and the United Kingdom (Grinker, Yeargin-Allsopp, & Boyle, 2011).

The systematic record review method involves a two-stage approach in which a screening phase occurs to identify an initial pool of children who may have ASD, then followed by a diagnostic confirmation stage (Grinker, Yeargin-Allsopp, & Boyle, 2011). The methods for both phases can vary widely, and validity is dependent upon the clinical and educational infrastructures in the location (Grinker, Yeargin-Allsopp, & Boyle, 2011). Elsabbagh et al describes the CDC's ADDM Network methodology as one appropriate and adequate for large samples, and a method likely to be employed in future surveillance efforts (Elsabbagh, et al., 2012). In the ADDM Network example, high-risk screening is employed, where educational labels are used in schools, and ICD codes in clinics, to target children most likely to be identified as having ASD. If a child with autism is not present in that first pool (that is, already identified under any disability label in a school, or have an ICD code attached to their health record), they will be a missed case. The method screens in the 8-year-old population, which is the age by which most

children with ASD have been found to be identified (Yeargin-Allsopp M. , et al., 2003). While the ADDM Network methods offer the advantages of being relatively cost effective (in comparison to screening in the general population), active in terms of case finding, and not reliant on an existing ASD diagnosis, there are important limitations to consider, including the potential lack of representativeness and the low sensitivity, positive predictive value, and incomplete case ascertainment, discussed below.

Representativeness is an important determinant of whether prevalence from a surveillance system can be generalized to populations beyond that system's catchment area. The population in the ADDM Network surveillance system represents less than 10% of the 8-year-old population in the United States (Centers for Disease Control and Prevention, 2015). Participating states are selected not for representativeness, but rather through a competitive grant process, chosen based on their ability to implement the CDC's rigorous protocol to achieve the primary goal of estimating and tracking autism prevalence trends over time (Centers for Disease Control and Prevention, 2014). Further, the methodology requires a catchment region of contiguous counties, usually containing a fraction of the population in a state. Selected counties may not reflect the demographics and other important characteristics in a state, and are often in urban areas. Further, with widely differing prevalence rates across sites, researchers have pointed out that local policies, resources, and awareness may impact prevalence rates, and rather than describing prevalence, the ADDM Network instead measures how educators and clinicians document and test for ASD (Mandell & Lecavalier, 2014). The authors suggest ADDM Network data is useful to describing disparities in diagnosis, age of

diagnosis, and clinical presentation, but not in providing true prevalence estimates (Mandell & Lecavalier, 2014).

There is a scarcity of literature evaluating the ADDM Network methodology, and only one evaluating the sensitivity and predictive value positive of the method; this study (Nonkin Avchen, et al., 2010) found the sensitivity of the system was estimated at 60% (95% CI: 45%-75%) and the predictive value positive was 79% (95% CI: 66%-93%), implying that a relatively large proportion (40%) of 8-year-old children with ASD were incorrectly identified as not having ASD, and approximately 1 in 5 children identified in the system as having ASD actually did not have ASD (Nonkin Avchen, et al., 2010). The authors note that accurately identifying cases of ASD is challenging even when rigorous methods are used; further, that the error rates may have been impacted by the sample including cases with low IQ as well as due to the types of tools used in the clinical evaluations. In the review by Elsabbagh et al (2012), the authors found similar issues with low sensitivity rates in other methods, including registries.

In Japan, Honda et al. (2005), conducted the screening stage from a general population pool in an attempt to reduce undetected cases, utilizing evaluations from 18 month old screenings (Honda, Yasuo, Imai, & Nitto, 2005). While able to provide high accuracy, this method requires vast resources and may reflect a participation bias. Registries, in which a person voluntarily includes oneself or one's child, are another way prevalence has been estimated. Registries are cost effective, but have the obvious limitation of an individual or family being knowledgeable about the registry, and opting to be included. Utilizing administrative data is another way prevalence has been estimated. Examining service records to estimate administrative prevalence has

significant limitations as well. Many groups may not access services for a variety of reasons; the low prevalence reported in Iranian and Omani studies, for example, is partially attributed to limited access to service centers (Elsabbagh, et al., 2012).

While ASD is generally understood not to differ across racial/ethnic groups, emerging research reports differences in prevalence; these differences may be attributed to issues previously discussed including diagnostic and identification practices, access issues, awareness, and resources (Elsabbagh, et al., 2012). Fombonne (2005) reviewed epidemiological studies on prevalence and found prevalence rates negatively correlated with sample size; higher prevalence tends to be reported with small sample sizes (Fombonne, 2005). In this same review, trends in prevalence greatly varied based on which case finding methods were employed, with administrative data providing lower estimates and intensive population-based screening resulting in higher estimates (Fombonne, 2005). Barnevik-Olsson, Gillberg, Fernell (2008) reported a prevalence estimate of three to four times higher for Somali children living in Sweden that children of other racial and ethnic groups in Sweden. Hewitt et al (2014) also found a higher prevalence of Somali children in Minneapolis, MN, though not a statistically significant difference to White children; both White and Somali children had a higher prevalence than other groups analyzed. Higher prevalence of ASD among Somali, Black African, and Black Caribbean children was also observed in a study in Britain (Hassan, 2012). As described by Fombonne (2005), the results of these studies should be interpreted with caution due to the low numbers of cases.

Grinker, Yeargin-Allsopp, and Boyle (2011) describe ongoing efforts to standardize the international epidemiologic approach to autism research, which would

depend on regional attributes and local capacity. The authors note the many challenges in achieving this, and that differing approaches would be required based on the country, including systemic case review, registry systems, and community canvassing in areas without a developed service system or awareness.

Families: arrangements, financial impacts, and socioeconomic factors associated with having a child with ASD

The following section focuses on literature that examines the impact of having a child with autism on a family unit in a number of important spheres: family arrangement, the financial impact, and socioeconomic factors associated with having a child with ASD.

The effects of a child with autism on the family. There is a large body of evidence that parents of children with disabilities experience many challenges. Parents of children with disabilities experience greater stress, more caregiving challenges, increased health problems, and higher rates of depression than those of typically developing children (Quine & Paul, 1985; Roach, Ormond, & Barratt, 1999). Research comparing mothers of children with ASD to mothers of children with other disabilities has demonstrated higher stress levels, anxiety, concerns about the effect of the disability on the family (Holroyd & McArthur, 1976; Bouma & Schweitzer, 1990), and an increased likelihood to perceive their child had a difficult temperament (Kasari & Sigman, 1997). Research extending to include fathers and mothers has found similar results, with parents of children with autism displaying significantly higher levels of stress, lower levels of marital intimacy (Fisman, Wolf, & Noh, 1989; Wolf, Noh, Fisman, & Speechley, 1989), and that mothers experienced greater depressive symptoms (Rodrigue, Morgan, & Geffken, 1990; Rodrigue, Morgan, & Geffken, 1992). One explanation offered for this

increased maternal distress was that mothers of children with autism perceived less feelings of attachment and closeness from their children (Hoppes & Harris, 1990), despite research studying the behaviors of children with autism suggesting attachment may not be impaired, yet displayed differently than other children (Dissanayake & Crossley, 1996). Consistent with the theoretical models this study employs, this suggests that perception is a vital factor in parental adjustment.

Citing a number of factors, researchers reviewing the effects of autism on the family describe ASD as a "greater threat" to the psychological well-being of the family than almost any other disorder (Seltzer, Krauss, Orsmond, & Vestal, 2001). Researchers (Gray & Holden, 1992) studying psychosocial well-being among a sample of parents of children with ASD found stressors are related to: a) the long and often arduous process involved with obtaining a diagnosis, at least partially due to the relative rarity of autism; b) the often extremely difficult behaviors of children with autism (such as temper tantrums and self-injury); c) the low level of understanding and tolerance for the challenging behaviors children with ASD may display, and the subsequent social isolation faced by families; and, d) the lack of a cure for autism and the existing treatments which require a large amount of time, energy, and patience from parents, other family members, friends, and professionals (Gray & Holden, 1992) (Seltzer et al., 2001).

Divorce in families with children with ASD. As prevalence of ASD has risen, so has the focus on the prevalence of divorce in parents of children with ASD. Addressing common speculation that there is a high divorce rate among parents of children with ASD (as much as 80% or more), researchers examined data from the 2007 National Survey of Children's Health, a cross-sectional population-based survey. This is the first study on

this issue to use a nationally representative sample, and the authors cited wanting to address an oft-cited statistic in media that 80% of marriages among parents of children with ASD end in divorce. Results showed no increased risk for living in a household not compromised of their two biological or adoptive parents compared to parents of children without ASD in the United States (Freedman, Kalb, Zablotsky, & Stuart, 2012). This study discussed associations between family makeup and divorce, though no temporal relationship was established, so it is questionable that divorce rates were actually ascertained. A study examining divorce rates among 391 parents of children ages eight to 30 with ASD in Massachusetts and Wisconsin found an overall divorce rate of 23.5% as compared to a rate of 13.81% among parents of typically developing children; a higher rate yet significantly lower than the alarming rate speculated to be 80% or more (Hartley, et al., 2010). These studies offer only two examinations in to the issue, and differ in their conclusions; further exploration is warranted. It is important to note the Hartley et al (2010) study only examined data from two states. Both of these studies affirmed previous findings that, while not concerned with divorce rates, suggest parental depression and resources in the form of supports are more important factors in predicting marital strife than severity of a child's ASD symptoms (Bristol, 1987; Freeman, Perry, & Factor, 1991). Neither study grounded their work in a theoretical framework.

Parental stress. There is a strong body of evidence on the increase in parenting-related stress and decreased marital satisfaction among parents of children with ASD (Abbeduto, et al., 2004; Bromley & Hare, 2004; Yamada, Suzuki, Tanaka, & Shindo, 2007; Bristol, Gallager, & Schopler, 1988). As suggest by Rodrigues et al. (2005), the marital relationship may remain intact despite the presence of factors that might other be

predictive of divorce (Rodrigues, Hall, & Finchman, 2005) . Financial, emotional, the fact that the spousal relationship may be their primary support, perception of isolation from others are all barriers which may preclude separation.

SES: education, income, and costs of ASD. Findings on the educational attainment of parents with children with ASD is somewhat mixed, with the evidence recently suggesting parents of a child with ASD have higher education and income status (possibly due to ascertainment bias) (Durkin, et al., 2010). There is a lack of research in this area (much of what has been done is outdated and subject to prior definitions of ASD), and what has been done recently has relied on ADDM Network data, not a nationally representative sample. Leo Kanner, when he first described autism, noted the high intelligence of the families coming to see him. Of course, these families also had the financial means to access his treatment. This perception of ASD as an upper class diagnosis remained for several decades, until researchers examined more representative samples and found wide ranges in parental education (here conceptually substituted for intelligence) and SES (Blacher & Christensen, 2011).

In a 2011 summary of the literature on the economic costs of ASD, Amendah, Grosse, Peacock, and Mendell include the following categories to organize the review: medical, nonmedical, and caregiver time costs, and the same structure is utilized here, and refers to both literature the authors reviewed as well as drawing on other relevant literature (Amendah, Grosse, Peacock, & Mandell, 2011). The authors undertook an extensive review of the available literature, offering a critical assessment of the various studies and the assumptions utilized therein. Of note, they excluded information on complementary and alternative medical (CAM) therapy. While complementary and

alternative medical (CAM) therapy (such as gluten or casein free diets, or horse therapy) are more utilized by parents with children with ASD, the costs are unknown (Wong & Smith, 2006). Higher parental education attainment is related with increased use of complementary and alternative medical therapies (Christon, Mackintosh, & Myers, 2010) while little is known about the overall prevalence, cost, and usage of CAM (Eisenberg, et al., 1993). It is understood that many of these therapies, while lacking efficacy, are paid for out-of-pocket, and therefore available only to those who can afford them.

Medical costs. Medical costs refer to the value of medical care provided by medical personnel and the staff working under their supervision, as well as prescription medications and laboratory tests (Amendah et al., 2011). Five recent studies calculate medical expenditures for children with ASD age 21 or under in the United States. All of these rely on either insurance claims or administrative data using the International Classification of Diseases, Clinical Modification (ICD-9-CM), either codes 299.0 and 299.8 (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Shimabukuro, Grosse, & Rice, 2008), or, all the 299 codes which also include children with disintegrative disorders and psychoses (Flanders, Engelhart, Pandina, & McCracken, 2007; Flanders, et al., 2006; Leslie & Martin, 2007; Mandell, Cao, Ittenbach, & Pinto-Martin, 2006). The cost data on children with ASD is outdated and there is a need for a contemporary understanding of the issue.

Related, a few studies have collected information on service utilization. Estimates of ratios of healthcare service utilization can be used to estimate relative medical costs (Amendah, Grosse, Peacock, & Mandell, 2011). A recent study linking data from the 2011 National Health Interview Survey data and Medical Expenditure

Panel Survey data found higher levels of health care office visits and prescription drug use compared with children without ASD (Lavelle, et al., 2014).

Two previous studies in the U.S. found that children with ASD had nearly twice as many nonemergency outpatient clinic visits on average, as well as a greater number of emergency department visits compared to typically developing children (Amendah, Grosse, Peacock, & Mandell, 2011; Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Gurney, McPheeters, & Davis, 2006). A third study estimated children with ASD had almost 13 times as many nonemergency outpatient visits and twice as many emergency department visits as typically developing children (Liptak, Stuart, & Auinger, 2006). The reasons for the discrepancy in numbers for outpatient nonemergency visits is unknown; there is variation across reports of medical expenditures and costs and data on trends in healthcare utilization is similarly inconsistent across studies (Amendah et al., 2011).

Nonmedical costs to families. Behavioral therapeutic interventions are recommended for children with ASD, and are more effective when started before age three. Applied Behavior Analysis (ABA) is the treatment approach for people with ASD with wide acceptance amongst health care professionals, and is used widely in schools and in treatment clinics (Centers for Disease Control and Prevention, 2015). A meta-analysis reviewing the effectiveness of ABA and early intervention for children with ASD found that, while children generally have meaningful benefits from the treatment, there is a wide range in individual responses to treatment, and most children still require specialized services (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). Early intervention utilizing ABA consists of children receiving 35-40 hours per week of one-on-one teaching for a period of two to four years and can cost on average $40,000 per

year per child, and may exceed $60,000 depending on factors such as family participation (Amendah, Grosse, Peacock, & Mandell, 2011).

Additional non-medical expenditures may include respite care, home modification, or socialization services. While not reviewed in the United States, two studies calculated the mean annual range for these expenditures. In the United Kingdom, costs from a pilot study of 17 children were reported at $5,500 (Jarbrink, Fombonne, & Knapp, 2003), and in Sweden from a survey of 33 children costs averaged $15,400 (Jarbrink, McCrone, Fombonne, Zanden, & Knapp, 2007).

Caregiver costs. As noted, parents of children with ASD experience greater stress levels than their counterparts with typically developing children. Using data from the nationally representative 2005-2006 National Survey of Children With Special Health Care Needs, researchers found that children with autism with special health care needs were more likely to live in families that report financial problems, and to need additional income for their child's medical care. Researchers found that 27% of families with a child with ASD (ages 3-17 years) report spending 10 or more hours a week providing care of coordinating care for their child. Further, respondents reported a family member reduced or stopped employment because of their child's disability (Kogan, et al., 2008).

Addressing gaps in the literature

Research on how autism impacts families is lacking in a number of ways. Many studies which have been completed on the topic use small sample sizes. It is unknown how changes to the definition of autism spectrum disorder in the latest DSM will impact prevalence rates. While research has suggested that families who have children with ASD experience higher household income and parental education statuses (Durkin, et al.,

2010), there is also research suggesting otherwise (Maenner, Arneson, & Durkin, 2009), with one study showing mothers experience lower educational attainment (Burd, Severud, Kerbeshian, & Klug, 1999). Research in this area is limited and has not been addressed through nationally representative samples. Further, the various family structures in which children with ASD reside is unknown, though it is known that certain family structures are more vulnerable to stress and economic hardship than others (Kalil & Ryan, 2010). While it is known that autism is costly to a family, the ways in which different family structures interact with public benefits is unknown. Using a large, nationally representative dataset will broaden the understanding of prevalence, the family structures of children with ASD, and how those arrangements and ASD impact a number of factors associated with SES. Research questions and hypotheses are included below.

Theoretical frameworks and models

The health of a family and the individuals therein are influenced by the interactions between individuals and family, and their context. Recognition that a crisis event affects both the family unit as a whole as well as the individual members is key to understanding responses across a range, from maladaptive and distress, to adaptive and resilient; family processes impact the outcome of family stressors (Walsh, 1998). Families may experience a number of protective or risk factors around belief systems, role models, organizational patterns, social support systems, economic resources, community context, and reactivation of past events which also contribute to their processes and outcomes in terms of a stressful, or a crisis event (Walsh, 1998; Van Hook, 2008). As an example, in terms of economic factors, poverty is a risk factor, while having adequate resources to buy food and to access medical care are protective factors.

Drawing on multisystem and multilevel approaches (the ecological framework), it is important to understand families in terms of their specific elements, demands, and contexts of stress and resources. Several theoretical frameworks contribute to understanding the experiences of families with a child with ASD, and are discussed below.

This study examines the experiences of families who have children with autism spectrum disorder (ASD), to develop a greater understanding of the impact having a child with ASD has on a family and certain social outcomes. It is hypothesized there will be differences in the experiences of families who have children with ASD, and those that have children without ASD. This study operates from a strengths-based perspective, which recognizes the family as capable of change, and focuses on identifying and building on assets rather than on deficits (Early & GlenMaye, 2000). With the principle of normalization (that people with disabilities should and can experience normal daily life as people without disabilities) at the foundation, the theory of social role valorization (SRV) offers valuable insights in to the roles that individuals with disabilities play in society. The theory argues that our assigned roles in society significantly impact how a person is seen and valued by others and society at large. For example, a homeowner who has a job which provides economic independence is valued more by society, and has a higher social role, than a person without those things (Wolfensberger, 2000). People with disabilities have long been marginalized, facing from many aspects of community which may result in higher social role valorization. Understanding a parent's reaction to a child being diagnosed with ASD through this lens helps to clarify an important way in which a family may interpret the diagnosis as a crisis. As further discussed below, the family

may mourn “what might have been” for their child and their place in society. If not throwing the family in to turmoil, it can at least be realized as an event which may temporarily destabilize the family’s normal routine and functioning, and subsequent ability for positive adaptation.

The theory for family stress and adaptation states that a family’s experience of stress, crises, and subsequent adaptation is an ongoing and dynamic process. The process of adaptation is impacted by the family’s response to a stressful event, their available resources, and presence of absence of effective coping strategies. Further, that adaptation exists on a continuum from positive adaptation to maladaptation, resulting in increased or decreased family functioning (McCubbin & Patterson, 1983; McCubbin & McCubbin, 1993; Patterson, 1988). This theory and updated model was developed out of work by Reuben Hill and colleagues, who developed a family stress theory and subsequent model after studying family responses to war, war separation, and eventual reunion after World War II (Hill, 1949).

Hill’s (1949) original framework, the ABCX model, detailed how the three factors of a stressor event, the family’s perception of that stressor, and the family’s existing resources interacted to predict the likelihood of a crisis occurring. The following outlines the concepts of the ABCX model. The stressor (A), is a life event or transition impacting the family unit that has the potential for changing the family social system. It is defined as distinct from stress and can occur in any aspect of the family’s life, including roles, functions, or goals. Existing resources (B), which all families are assumed to have at least some level, are the family’s use of intra-familial and community system. These may be adequate or inadequate depending on the nature of the stressor

event or the family's level of functioning. The perception of the stressor (C) is defined as the meaning the family assigns to the crisis event and the total circumstances that lead to the crisis. The crisis event (X) is defined as the demand for change; a continuous variable that reflects the sum of the family's disorganization, turmoil, and disruption as triggered by an event. The model regards crisis as the family's inability to retain stability. If the family were able to meet the demands of the stressor then the crisis may be averted.

McCubbin and Patterson developed the Double ABCX model, adding post-crisis variables (for example, coping mechanisms) to explain how families recover from crisis and achieve adaptation over time (McCubbin & Patterson, 1983). The model posits that families facing a stressor event experience phases of adjustment and adaptation, exemplified by a range of processes in which different variables interact. Subsequently, McCubbin and McCubbin (1998) built on this work and developed the Resiliency Model, emphasizing the family's relational processes of adaptation and family's appraisal process that involve culture and ethnicity and that facilitate the ability to institute new patterns of functioning and achieve harmony while promoting the well-being and development of family members. The Resiliency Model has two main phases: adjustment (minor changes) and adaptation (major changes), and like the ABCX model, there is a second round of events where the family responds to stressors (aA) interacting with resources (bB).

There are explicit assumptions related to this work. First, that over the course of life, families will face hardships and changes as a natural and predictable aspect of family life. Next, that families develop basic competencies, patterns of functioning and

capabilities to foster the growth and development of family members and the family unit, and to protect the family from major disruptions in the face of transitions and changes. The third assumption is that families develop basic and unique competencies, patterns of functioning, and capabilities designed to protect the family from unexpected or non-normative stressors and strains to foster the family's recovery following a family crisis or major transition or change. Next, that families draw from and contribute to the network of relationships and resources in the community, including ethnic and cultural heritage, particularly during periods of family stress and crises. Finally, that families faced with crisis situations demanding changes in the family's functioning work to restore order, harmony and balance even in the midst of change. Implicitly, it is assumed that families like to live an orderly and balanced life and are willing to cope with stress. Further, that family variables are existent prior to the connections to each other, and they can be clearly distinguished (McCubbin & McCubbin, 1996).

The Double ABCX model, like systems theory, views the family as the system in which experiences of one family member impact the experiences of other family members. The integral influence of the family system on each individual member's development (and vice versa) is highlighted and interactions of the different aspects are viewed as dynamic processes rather than static. There are a few studies which have specifically tested or applied use of the Double ABCX model in research related to parenting children with autism spectrum disorder and related disabilities. Bristol (1983) demonstrated the effectiveness of the model in predicting successful adaption in mothers of children with ASD, as seen in the outcomes of positive marital adjustment, few maternal depressive symptoms, and rating of family functioning (Bristol, 1987).

Variables as applied to the model include severity of the disability, other family stresses, family resources of cohesion and social supports, family definition of the disability, and adequacy of coping patterns (Bristol, 1987).

Another study examined the relationship between maternal adjustment and the Double ABCX model in a sample of mothers of children diagnosed with Asperger's syndrome[1] in Brisbane, Australia (Pakenham, Samios, & Sofronoff, 2005). Researchers used various questionnaires to assess factors such as stress responses, social supports, appraisal of the situation, and coping strategies, in line with the Double ABCX model, and found that better maternal adjustment was related to higher levels of social supports, coping, and lower levels of stressor severity (child's behavior problems), pile up of demands, and negative coping behaviors (such as disengagement) (Pakenham, Samios, & Sofronoff, 2005).

While not specific to ASD or the United States, researchers in Finland selected 20 variables based on the Double ABCX model to explain parental stress of fathers and mothers caring for a child with intellectual disability (Saloviita, Italinna, & Leinonen, 2003). An estimated 38% of individuals with ASD also have an intellectual disability (Christensen, et al., 2016), though this study did not distinguish if children had a co-occurring ASD in this sampling. Parents were given a questionnaire and independent variables such as *age of the child*, *severity of the disability*, and *informal* and *formal social supports* were tested to determine their impact on the outcome variable of *parental stress*. These 20 variables were ultimately reduced through principal component analysis

[1] As of DSM-5, many individuals formerly diagnosed with Asperger's Syndrome are now diagnosed under Autism Spectrum Disorder (American Psychiatric Association, 2013). Asperger's Syndrome is not a diagnosis in DSM-5.

to eight variables: *marital relationship, adaptive behavior of the child, negative coping strategies, definition of situation as 'catastrophe,' informal support, positive coping strategies, formal support,* and, *locus of control.* Overall, the results indicate that the way in which parents define their situation and the various resources available to them are more important in predicting parental stress than other factors. Like previous work, results suggest the properties of the child, or severity of the disability, is less of a predictor of stress and negative family adaptation than resources or the way the family defines the situation (Bristol, 1987; Saloviita, Italinna, & Leinonen, 2003).

Of note, each of the studies focusing on the Double ABCX model of adjustment is related to parental role; two are specific to mothers' experiences (Bristol, 1987; Pakenham, Samios, & Sofronoff, 2005), while the third considers both fathers and mothers (Saloviita, Italinna, & Leinonen, 2003). The literature has not assessed the model within the whole context of the family living with a child with ASD, such as amongst siblings, for example.

Related to the issues of stressors, coping, and adjustment as described in the Double ACBX model is the ambiguous loss theory. Ambiguous loss is a loss that remains unclear, lacking information, with an unknown status, and is traumatizing for most that experience it. Out of the stress and resiliency-focused ambiguous loss theory emerged two models for understanding absence: physical absence with psychological presence and psychological presence with physical absence (Boss, 2007). Boss notes family members describe the first type as "leaving without goodbye" and the second type as "goodbye without leaving" (Boss, 2007). Resilience is a key factor in this theory, and is described as, when coupled with hope, paramount to being able to accept the loss

and move on with life (Boss, 2006). Resiliency is bolstered by a number of factors, including internal and external resources. From this perspective, the links to the Double ABCX model are clear.

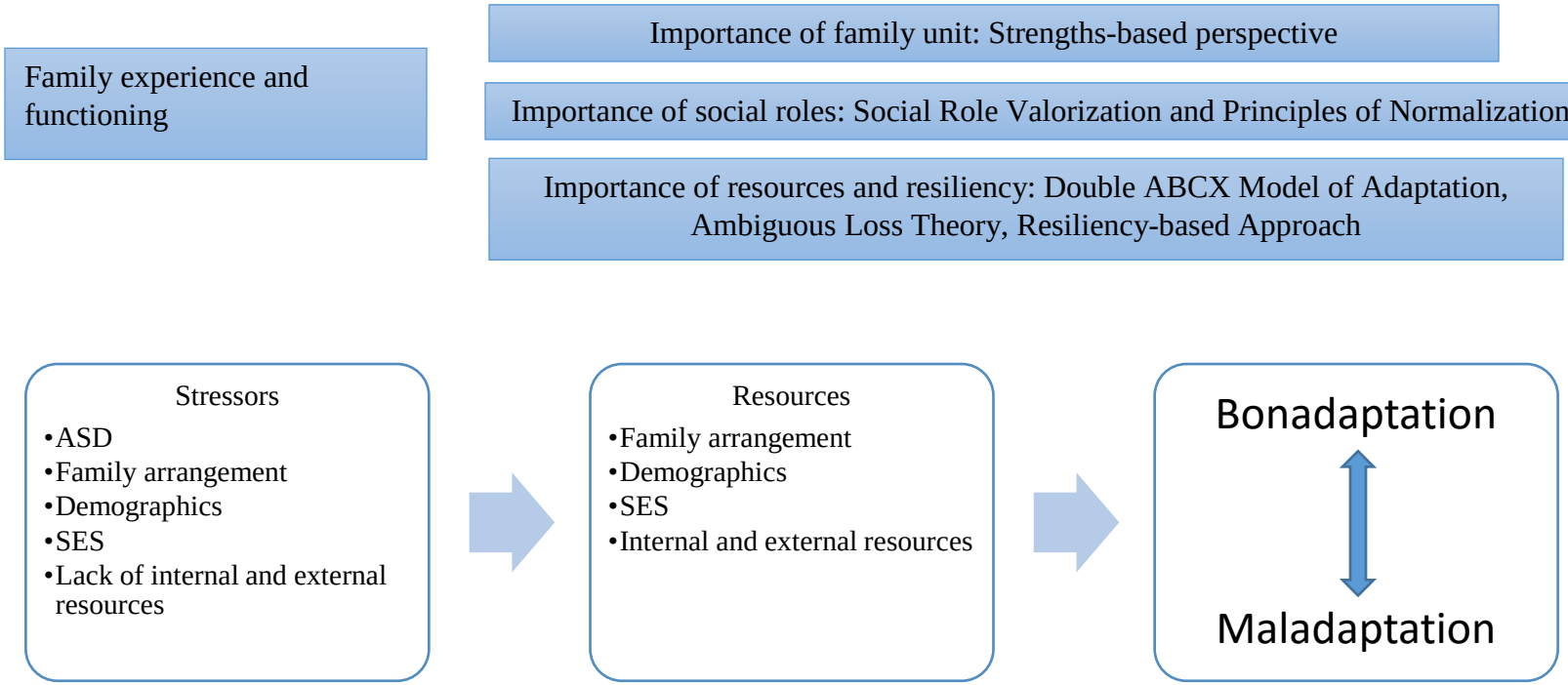
Factor (C) in the Double ABCX model is the perception or appraisal of the stressor (A). This strongly relates to the concept of boundary ambiguity in the ambiguous loss theory, and is useful in further understanding how families adjust to a stressor. Boundary ambiguity is defined as a lack of understanding who is in or out of the system. While the ambiguous loss as an external event is assumed to be neutral, how it is perceived is not; the higher the degree of boundary ambiguity, the more negative the outcomes (Boss, 2007). O'Brien (2007) proposes that a diagnosis of ASD is likely to be experienced by a family as ambiguous loss. Derived from ambiguous loss theory, the author tested the hypothesis that higher levels of identity ambiguity in mothers are linked to higher levels of depressive symptoms and perceived stress independent of the severity of the child's ASD diagnosis, and found it to be supported (O'Brien, 2007). In the study, identity ambiguity is described as an aspect of boundary ambiguity, more specifically, the ambiguity between family member's identities (O'Brien, 2007). While described as a study to understand family experiences, the interviews were conducted with mothers and the questions were focused on the mothers' experiences. The author explains how factors such as *loss of relationships* can create situations of ambiguity with a family, such as not participating in traditional ways a child does, thus resulting in a situation of ambiguous loss. Further, because the child with ASD is often not easily identified by physical markers, others in the family's social network may discount the diagnosis, undermining parents (O'Brien, 2007), and, possibly, impacting the way in which they participate with

their wider community. These examples share obvious connections to the Double ABCX model: the ambiguous loss is a stressor, the impact on relationships is related to resources as well as perceptions.

The family stress model, and subsequent Double ABCX model, as well as the resiliency-based perspective and the ambiguous loss theory are particularly useful for understanding families with children with ASD. In particular, the concepts and approaches provide lenses for identifying appropriate data for analysis and developing and evaluating interventions aimed at assisting and understanding the experiences of families with children with ASD. In particular, the Double ABCX model is relevant as the model accounts for the pile up of additional family stresses that may complicate adaptation, as well as the resources and coping strategies that the family may employ to manage the potential crises, the meaning the family assigns to the event, and acknowledges the range of possible outcomes, positive and negative. Understanding family response and outcomes via this, and the other relevant theories and models discussed, allows for greater understanding of family outcomes for those families with a child with autism as well as informing the design of this study.

Conceptual model. The conceptual model in Figure 2 details the relationships, based in relevant theory and supporting literature, that imply an association between variables used in this study. It is important to note that this study does not attempt to establish causation, rather associations between variables, which are also identified in Figure 2. Research models are developed to account for relationships between variables at a conceptual level and to guide the design of a study.

Figure 2. Conceptual Model



A central goal of this study is to determine the associations between different family structures which have children with ASD and outcomes related to SES. SES is often accounted for in research by using education and income data. The literature review included a number of studies which detailed the stress a family undergoes as a result of having a child with ASD. Additionally, research supports the idea that resources (such as socioeconomic status and access to public benefits) are a vital factor in the adjustment of a family. Simply stated, having access to resources reduces stress and promotes positive adjustment. Family stress adaptation theory, in particular the Double ABCX Model of Adaptation, identifies resources as important to a family's resilience (Hill, 1949; McCubbin & McCubbin, 1996; McCubbin & Patterson, 1983). Related, the ambiguous loss theory, offers important insights in to how the diagnosis of ASD is a stressor event which requires a family to adjust, and the important ways that resources, both internal and external to the family, play an important role in the family's ability to adjust, to be resilient (Boss, 2006; Boss, 2007).

Finally, consideration for the theory of social role valorization and the related principle of normalization is utilized to frame the way in which a family may understand the diagnosis of ASD as something that may create a marginalized outsider status for their family member with ASD (Wolfensberger, 2000), and indeed, for the family—this being undoubtedly a root stressor. At least one research study has directly tested for the concepts of resiliency using the ambiguous loss model (O'Brien, 2007), and found, consistent with other research, that factors associated with resources, that is, those things that promote resiliency, are vital to a family's positive adaptation. Likewise, the Double ABCX model of adaptation has been tested in families with children with ASD and

again, resources, both external and internal emerge as important to the health of the family. The theoretical frameworks were used to identify variables with which to test a number of hypotheses around the family experience. Understanding the resources of a family is useful in knowing how well-equipped a family is to adapt to having a child with ASD.

This study aims to increase understanding of the experiences of families with a child with ASD. Several methods are used to accomplish this, including providing a prevalence estimate, providing population estimates across different family structures, and running a series of logistic regression models to test associations between family structures of families with a child with ASD and parental education, income, and public benefit usage. Research has shown that certain family structures are related to greater levels of stress and more vulnerabilities in terms of access to supports and resources. Having a higher SES is associated with better outcomes across a number of important spheres, and is recognized as a protective factor for families. Access to supports which increase family stability is particularly important for families with children with ASD, who research has shown experience greater levels of stress than other families. It is through these theoretical lenses and supporting literature that the central aims, research questions, and variables for this study are derived.

Research questions

Research Questions and hypotheses. Research suggests there are a number of ways ASD impacts a family's experience. The following research questions are designed to gain a greater understanding of the impact of having a child with ASD on family social outcomes.

1. What is the two year pooled prevalence rate of families with children with ASD?

Reasoning. Establishing a prevalence estimate using pooled data both provides an updated and stable estimate, and acts as an anchor for understanding the scope of the population being studied.

2. Do family structures of children with ASD differ from the general population?

   Hypothesis RQ2: *There will be differences across family structures for families with children with ASD compared to families with children without the diagnosis.*

3. Does having a child with ASD relate to higher odds (likelihood) of specific family structures?

   Hypothesis RQ3: *Having a child with ASD results in lower likelihood of two-parent households and higher likelihood of single mother households.*

Reasoning. There is not a large breadth of research on the family structures of children with ASD. Based on what has been done on family stress related to having a child with ASD, it suggests that these families may be more vulnerable to divided family units. The two studies which have more closely addressed this topic, using different samples and methods, have had different results (Freedman, Kalb, Zablotsky, & Stuart, 2012) (Hartley, et al., 2010).

4. What are the effects of ASD and family structures on public benefit usage?

Hypothesis RQ4a: *Two parent families with children with ASD will have more public benefit usage than families with children without the diagnosis.*

Hypothesis RQ4b: *One parent families with children with ASD will have more public benefit usage than families with children without the diagnosis.*

Reasoning. Research has established that ASD is costly to families and that public benefits are an important support that can offset financial difficulties. Research has also shown that single parent households are more vulnerable to financial hardship. As a qualifying factor for many public benefits, it is reasonable to believe that there is a higher likelihood that families with a child with ASD would access public programs.

5. What are the effects of ASD and family structure on parental educational attainment?

   Hypothesis RQ5a: *Two parent families with children with ASD will have higher educational attainment than two parent families with children without the diagnosis.*

   Hypothesis RQ5b: *One parent families with children with ASD will have lower educational attainment than two parent families with children with no ASD diagnosis.*

6. What are the effects of ASD and family structure on household income?

   Hypothesis RQ6a: *Two parent families with children with ASD will have higher income than two parent families with children without the diagnosis.*

   Hypothesis RQ6b: *One parent families with children with ASD will have lower income than two parent families with children with no ASD diagnosis.*

Reasoning. ASD has been thought of as a high SES condition. Recent research reviewing income using ADDM Network data and census block data found that families

with children with ASD lived in block groups with higher median household income and higher adult educational attainment than those families with children with no ASD diagnosis (Durkin, et al., 2010). Research also shows that single parent families face more economic hardships than other family structures (Kalil & Ryan, 2010). One case control study found lower educational attainment among mothers with children with ASD by matching birth certificate records of children with DSM criteria for ASD (Burd, Severud, Kerbeshian, & Klug, 1999).

Chapter IV: Methods

Design

This study has several purposes. First, it seeks to understand and estimate the family structures that children with ASD reside in and compare these structures to the families with a child that does not have autism. Next, this study seeks to explore the effects of ASD on family and various socioeconomic outcomes. This study is correlational in nature, and will rely on a series of statistical analyses, including a prevalence estimate, population estimates, and a series of logistic regressions to show if and how ASD relates to these domains using NHIS survey data.

Source of data and data collection procedures

This study utilizes the National Health Interview Survey (NHIS) data from 2014 and 2015. The NHIS is a nationally representative annual cross-sectional household interview survey conducted by the Centers for Disease Control and Prevention (CDC). This survey is the primary data source studying illness and disability of the civilian non-institutionalized population of the United States. It excludes persons in long-term care facilities, correctional facilities, and U.S. nationals living abroad. The survey program is widely used to monitor trends in illness and disability and to understand related demographic and socioeconomic factors, such as determining barriers to accessing and using appropriate health care. The NHIS is unique among national U.S. surveys because it routinely collects data on health behaviors, health conditions, health care utilization, and health care coverage for the United States, including information about disabilities. The NHIS is divided in to various core questionnaire sections and topics; these sections group questions in to broad and specific categories.

The NHIS is the principal source of information for studying illness, disability, and health of the civilian noninstitutionalized population of the United States. The data are widely used in public health and public policy to understand related demographic and socioeconomic factors, and to evaluate programs (CDC/National Center for Health Statistics, 2016).

The NHIS questionnaire is revised periodically and, since 1997, consists of a Core questionnaire that remains largely unchanged. Additional supplements, such as those sponsored by outside federal agencies, may be included and vary from year to year. Four main components make up the Core questionnaire; these are the: Household Composition section, Family Core, Sample Child Core, and Sample Adult Core. Table 3 provides the various questionnaire sections for the 2014 and 2015 NHIS, unchanged from 2014 to 2015, the corresponding three-digit acronym (section code), and the description titles.

Table 3. 2014 and 2015 NHIS Core Questionnaire Sections

Section	Acronym	Description
Household	HHC	Household composition
Family Core	FID	Family identification and verification
	FHS	Health status and limitation of activity
	FIJ	Injury/poisoning
	FAU	Health care access and utilization
	FHI	Health insurance
	FSD	Socio-demographic
	FIN	Income and assets
Sample Child Core	CID	Child identification and verification
	CHS	Conditions, limitation of activity and health status
	CAU	Health care access and utilization
Sample Adult Core	AID	Adult identification and verification
	ASD	Demographics
	CAN	Conditions
	AHS	Health status and limitation of activity
	AHB	Health behaviors
	AAU	Health care access and utilization
	ASI	Adult selected items
Recontact	REC	Recontact information and follow-up

Chart adapted from 2014 and 2015 NHIS Descriptions (Centers for Disease Control and Prevention, 2015; Centers for Disease Control and Prevention, 2016).

The Household Composition section collects information on basic demographic and relationship information about all persons in the household, defined as an occupied housing unit. The Family Core is administered separately for each family in the household, and collects information on all persons in the family, defined as an individual

or group of two or more related persons who are living together in the same household. Additional definitions of "family" are included, such as unmarried couples who are living together. The topics on the Family Core questionnaire include socio-demographic characteristics, basic indicators of health, activity limitations, injuries, health insurance coverage, and access to and utilization of health care services.

If a child or children are present in the family, then one "sample child" aged 17 or less is randomly selected and one "sample adult" aged 18 or more is randomly selected. Information about the sample child is collected from a knowledgeable adult and information about the sample adult is collected from the sample adult themselves. These utilize the Sample Child Core and Sample Adult Core questionnaires, respectively. While the questionnaires differ in some items for children and adults, both collect basic information on health status, health care services, and health-related behaviors. When fielded, supplementary questions about the sample child and sample adult provide additional information (Centers for Disease Control and Prevention, 2015; Centers for Disease Control and Prevention, 2016).

The NHIS collects demographic and basic health information for all family members. In addition, the NHIS randomly samples one adult and responses are self-reported; if a respondent is unable to participate due to physical or cognitive limitations, a proxy who knows the respondent is allowed to respond. Additionally, a knowledgeable adult (usually the parent or guardian) responds for the randomly sampled child (Centers for Disease Control and Prevention, 2015).

Sampling and interviewing are continuous throughout each year, and conducted in face-to-face interviews in respondents' homes. Follow up may be conducted over the

telephone, or when a respondent requests a telephone interview, or when road or travel conditions would prohibit a personal visit. Due to this interview format, a large simple random sample would be prohibitive. Instead, NHIS survey planners utilize multistage sampling techniques to select by dwelling units and to partition the target universe in to several nested levels of strata and clusters.

The current NHIS sampling plan, which is revised after each decennial census, consists of a sample of 428 primary sampling units (PSUs) drawn from approximately 1,900 geographically defined PSUs that cover the 50 states and the District of Columbia. A PSU consists of a county, a contiguous group of counties, or a metropolitan statistical area. The total NHIS sample is subdivided in to four separate panels such that each panel is representative of the U.S. civilian noninstitutionalized population (Centers for Disease Control and Prevention, 2015). Finally, the CDC provides proper statistical weights for researchers, to ensure the sampling procedures are accounted for in population estimation. The Sample Person Weight represents the inverse probability of selection into a sample adult/child supplement, adjusted for non-response with additional post-stratification adjustments using the Census Bureaus population control totals (MN Population Center, 2016).

The NHIS sample size can vary from year to year, and may be reduced or augmented depending on budget or available supplementary funding. The normal annual sample size for the 2006-2015 sample design is approximately 35,000 households containing 87,500 persons. In 2011-2015, the NHIS sample size was augmented in 32 states and the District of Columbia to increase the number of states for which reliable state-level estimates can be made. (Centers for Disease Control and Prevention, 2015)

(Centers for Disease Control and Prevention, 2016). The public use data files for the 2014 NHIS contain data for 44,552 households containing 112,053 persons in 45,597 families. The number of sample children is 13,380, and the number of sample adults is 36,697. A knowledgeable proxy answered for the sample adult in 488 cases (Centers for Disease Control and Prevention, 2015). For the 2015 NHIS, the public use data files contain data for 41,493 households containing 103,789 persons in 42,288 families. The number of sample children is 12,291 and the number of sample adults is 33,672. A knowledgeable proxy answered for the sample adults in 476 cases (Centers for Disease Control and Prevention, 2016).

Response rates. In the 2014 NHIS, the final response rates for the relevant core components are as follows: 73.1% for the family component; 66.6% for the Sample child component; and 58.9% for the Sample adult component. The total household response rate was 73.8%; 17.6 percentage points of the 26.2% non-interview rate were the result of respondent refusal and unacceptable partial interviews. In the 2015 NHIS, the final response rates for the relevant core components are as follows: 69.3% for the family component; 69.3% for the Sample child component; and 55.2% for the Sample adult component. In all cases, final response rates were calculated by dividing the total number of completed sample interviews by the eligible sample cases (family, Sample child, or Sample adult). The total household response rate 70.1%; 20.4 percentage points of the 29.9% non-interview rate were the result of respondent refusal and unacceptable partial interviews. The remaining 9.5 percentage points were primarily due to failure to locate an eligible respondent (Centers for Disease Control and Prevention, 2016; Centers for Disease Control and Prevention, 2015).

Population and Sample Size

The multi-level structure of the NHIS data allows for investigations of family units by way of data that links a child to their family unit. Additionally, parent or guardian reports of a professional diagnosis of autism allows researchers to understand the differential effects of a diagnosis on various outcomes. As such, the population of interest in this study is families of the civilian non-institutionalized population of the United States that have children between the ages of three to 17 years. Families with younger or older children residing in the household were excluded from survey eligibility.

The total pooled sample of the NHIS survey includes 215,842 households. After restricting the sample to include only those with children between the ages of three and 17, the pooled sample included 22,697 subjects, 22,208 with children that do not have autism and 489 with children that do have autism.

Changes to measures for ASD in the NHIS. The NHIS has undergone changes to the measures surrounding identification of children with autism. From 1997 through 2010, sample children with autism were identified as part of a 10-condition checklist. Respondents were asked to read the list and report whether a doctor or other health professional has ever told them that the child had any of the listed conditions, and if so, to identify which conditions were diagnosed. Respondents were not specifically asked about each condition. From 2011 to 2013, the checklist process was maintained, but the wording for the condition was changed from "autism" to "autism/autism spectrum disorder." In 2014, the condition became a standalone question so that respondents for sample children were specifically and directly asked about ASD. This revision utilized

the conditions defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR), and also aligned the question with those found in other national surveys, in particular the National Survey of Children's Health. Specifically, in the NHIS, parents were asked, "Did a doctor of health professional ever tell you that [child's name] had autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?" Figure 3 details the differences in the question wording between 2011-2013 and 2014-2015.

Figure 3. Wording for autism question in the NHIS

Question wording in 2011-2013

Autism spectrum disorder

Looking at this list, has a doctor or health professional ever told you that [child's name] had any of these conditions?

Down syndrome

Cerebral palsy

Muscular dystrophy

Cystic fibrosis

Sickle cell anemia

Autism/autism spectrum disorder

Diabetes

Arthritis

Congenital health disease

Other heart condition

Question wording in 2014-2015

Autism spectrum disorder

Did a doctor or health professional ever tell you that [child's name] had autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?

The change in wording (and being a standalone question) in 2014 and beyond offers more specific details on what constitutes an ASD. Previously, the 10 condition checklist was provided after questions about intellectual and developmental disabilities (Zablotsky B. , Black, Maenner, Schieve, & Blumberg, 2015). Research suggests that order and contextual changes to a survey question can influence respondent interpretation and subsequent responses, resulting in changes to the data captured and the resulting estimates (Tourangeau, Rips, & Rasinski, 2000). An evaluation of the change in wording and ordering of the ASD question in the NHIS suggests there was an impact in respondent reporting as prevalence of ASD rose in the 2014 questionnaire to 1 in 45 from a previous average of 1 in 80 across years 2011-2013. Further, the researchers suggest that as the 2014 NHIS prevalence data more closely aligns with other ASD tracking systems (namely, the ADDM Network and the NSCH) than the 2011-2013 data, the 2014 data are more likely to provide valid estimates (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015).

Data access and pooling. The NHIS program data is accessed via the Integrated Health Interview Survey (IHIS) data managed by the Minnesota Population Center (MPC). The MPC has constructed a reliable and tested linking process of the multilevel surveys into an integrated dataset that links household data to the individuals residing in the household. This system allows researchers to customize an NHIS dataset and codebook with only relevant variables. Researchers can gain access to the dataset in an easily retrievable format almost immediately via the MPC online data tool. The MPC system also provides a streamlined mechanism to construct and merge 2014 and 2015 data into a single file by capturing common variables across multiple sample years. The

MPC also constructs a downloadable file and syntax to upload into various statistical packages, as well as provides a number of technical assistance and guidance documents as resources to assist both in using the NHIS data and the MPC online retrieval tool.

Variables. Table 4 presents the coding type, uses, and response options for variables used in this study. Only four of the original NHIS variables were used in combination to construct an entirely different variable. See Appendix A for NHIS variable names and definitions.

Constructed variables. The first newly constructed variable merged ASD status and family structure to create a categorical variable. Using NHIS codes AUTISMEV and FAMSTRUC1F, a new variable (Autism by family structure) was created. This allowed for creating four mutually exclusive groups with enough data to have statistical power to determine the effects of autism and family structure on an outcome. This variable was used as an independent variable and identifies single parent and two parent households for children with and without ASD. This results in a total of four mutually exclusive groups: two parent households with a child without an ASD diagnosis, single parent households with a child without an ASD diagnosis, two parent households with a child with an ASD diagnosis, and single parent households with a child with an ASD diagnosis. Table 4 shows the various family structures in the variable utilized. Additionally, mother's education or father's education was utilized to identify the parent with the highest level of education in the household.

Adaptations were made to the Race variable in order to have more meaningful groups. By adapting the variable, the limited number of subjects with autism was not

spread so thin as to restrict statistical power. The Race variable was grouped in to White, Black, and Other.

Table 4. Variable name, construction, type, coding, and response options

Name	Original variable for construction	DV	IV	Coding used	Response options
ASD status	-	*		Dichotomous	No ASD (0), ASD (1)
Family arrangement	-			Categorical	Single parents: mother only, father only, other single adult. Two parents: both biological, one biological & step parent, one biological & cohabiting partner, one biological & other adult, and two other related & unrelated adults.
Two-parent	Family arrangement	*		Dichotomous	Single parents (0), Two parents (1)
Single mother	Family arrangement	*		Dichotomous	Two-parents (reference grp), single mother (1)
ASD by family structure	ASD status & family arrangement		*	Dummy coded	Two parent - no ASD (reference grp), one parent - no ASD, two parent - ASD, one parent - ASD).
Highest education in household	-	*	*	Dummy coded	No high school diploma (reference grp), high school diploma to some college, AA/Voc degree, Bachelor's degree, Master's degree or higher
Highest education: high school or less	Highest education in household	*		Dichotomous	Higher than high school (0), high school or less (1)
Highest education: vocational/AA degree	Highest education in household	*		Dichotomous	No Voc/AA degree (0), Voc/AA degree (1)
Highest education: Bachelor's or more	Highest education in household	*		Dichotomous	Less than Bachelor's or higher (0), Bachelor's degree or higher (1)
Race	-		*	Dummy coded	Dummy coded: White (reference grp), Black, & other
Hispanic	-		*	Dichotomous	Not Hispanic (0), Hispanic (1)

Below poverty	-		*	Dichotomous	Above poverty (0), below poverty (1)
Family income below $50,000	-	*		Dichotomous	Above $50,000 (0), below $50,000 (1)
SSI benefit use	-	*	*	Dichotomous	Did not use SSI (0), did use SSI (1)
SNAP (food assistance)	-	*	*	Dichotomous	Did not use SNAP (0), did use SNAP (1)
Own a home	-		*	Dichotomous	Did not own a home (0), did own a home (1)
Rental assistance	-	*	*	Dichotomous	Did not use rental assistance (0), did use rental assistance (1)
Public Health Insurance	-	*	*	Dichotomous	Did not use public health insurance (0), did use pubic health insurance(1)

Note. DV = Dependent variable; IV = Independent variable

Analysis plan

As a low incidence disability, the comparative effects of autism on various outcomes can be difficult to detect using a single year of NHIS data due to low power. Thus, by pooling the most recent years of NHIS data that use common definitions, it is possible to develop two-year population estimates that tend to be more stable, as well as gain power for additional modeling and comparisons. Analyses are conducted using SPSS version 24 statistical software. The software's descriptive, cross-tabulation, and logistic regression procedures are utilized.

Population estimation. Using CDC provided sample weights, this study will exploit the power of the NHIS dataset to develop population estimates, presented via percent and standard errors. These population data are integrated into the various analysis stages. When relevant, they are presented side-by-side unweighted statistics.

Statistical approach. Descriptive analyses present summary breakdowns of characteristics across all variables. Chi-square test of a cross-tabulation table will be used to examine the extent to which family structures vary for individuals with ASD and the general population. These initial analyses provide a summary of the demographic, SES, family structure, and economic characteristics that are investigated.

Outcome variables undergo further testing using multivariate regression analyses of the various outcomes. Due to the dichotomous outcomes analyzed, the study uses a series of logistic regressions. A summary of variables entered into each of the logistic regression models are presented in Table 5 and Table 6. The $p < .05$ value is used to determine significance.

Logistic regression goodness of model fit is evaluated using a Hosmer-Lemeshow test. This approach is known to be highly sensitive to large sample sizes due to increases in power, resulting in the rejection of good logistic models. A review of the contingency table is conducted to evaluate the model fit. That the model fails the Hosmer-Lemeshow test doesn't mean tests of association between the outcomes and predictors are invalid; rather, it means that in each analysis, predictors are limited in what they can capture. Additionally, a strength of logistic regression is that the lack of fit does not inflate standard errors.

Table 5. Logistic Regression Model Variables, Family and Benefit Programs

	Logistic models/dependent variables					
	Family		Benefit Programs			
Independent variables	Single mother	Two-parent	SSI	SNAP	Rental Assist.	Health Ins.
Autism	*	*				
Autism by family Structure			*	*	*	*
Race	*	*	*	*	*	*
Ethnicity	*	*	*	*	*	*
Education	*	*	*	*	*	*
SSI in last year				*		*
Below poverty	*	*				
Own home	*	*		*		*

Table 6. Logistic Regression Model Variables, Education and Income

	Logistic models/dependent variables			
	Education			Income
Independent variables	HS or less	AA or voc.	BA or higher	Below $50,000
Autism by family Structure	*	*	*	*
Race	*	*	*	*
Ethnicity	*	*	*	*
Education				*
SSI in last year				*
Below poverty	*	*	*	
Own home	*	*	*	*

Summary. While it is known that having a child with ASD results in increased stress for many families, less is known about the actual impact of ASD and family structure upon a number of important indicators. Utilizing the NHIS program provides an opportunity to understand the experiences of families with a child with ASD in ways unavailable from other national surveys.

Chapter V: Results

The following chapter presents results from the analyses of the data. The purpose of this study is to examine the experiences of families with children with autism spectrum disorder by testing for associations between various factors related to SES and having a child with ASD in the family.

Descriptive Statistics

Demographics. The sample includes 22,697 families with children ages 3 to 17 surveyed in the 2014 and 2015 NHIS. Of these, 2.2% (489 households) are identified as having a child with ASD. The majority of these families are identified as White (73.6%), with Black and Other making up 26.2% of the sample. The ethnic makeup is identified as 71.4% Not Hispanic and 28.6% as Hispanic. Table 7 provides an overview of the demographics of subjects included in this study.

Table 7. Demographics
(*N* = 22,697)

	#	%
ASD		
Autism	489	2.2
No autism	22,208	97.8
Race		
White	16,715	73.6
Black	3,671	16.2
Other	2,311	10.2
Ethnicity		
Not Hispanic	16,205	71.4
Hispanic	6,492	28.6

Family structure. Table 8 provides an overview of the family structure of the overall sample group. Of the 22,697 families, 77.9% are identified as married or otherwise partnered with two parents/adults. Within this group, married or unmarried parents account for 42% of the sample, these being the biological or adoptive parents of the sample child. Families structured with a parent and a step parent, cohabitating partner, or other adult make up 35.9% of the group. Within this group, 26% are made up of one parent (biological or adoptive) and an other related adult—this may include a grandparent or other relative. One parent or adult families account for 18.2% of the sample population, the majority of these being headed by the mother (14.5%), with a father or other single adult accounting for 3.7% of the sample. Families made up of other related and unrelated adults makeup 3.9% of the population, and include either relatives or unrelated adults.

Table 8. Family structure
(*N* = 22,697)

Family Structure	#	%
One Parent/Adult		
Mother	3,300	14.5
Father	598	2.6
Other single adult	241	1.1
Two Parents/Adults		
Married/unmarried	9,534	42.0
Parent & step parent	1,358	6.0
Parent & co-hab. partner	879	3.9
Parent & other adult	5,911	26.0
Other related and unrelated adults	876	3.9

ASD diagnosis by family structure.

The breakdown of family structure by ASD diagnosis is described in Table 9. Families with a sample child with no ASD diagnosis account for 97.9% of the sample; families with a child with ASD account for 2.1% of the sample, or 489 families.

Table 9. ASD diagnosis by family structure
(*N* = 22,697)

ASD x Family Structure	#	%
Two parents - No ASD	11,546	50.9
Two parents – ASD	225	1.0
One parent – ASD	264	1.1
One parent - No ASD	10,662	47.0

Socioeconomic indicators. Socioeconomic indicators utilized in the study include the poverty threshold, receipt of Supplemental Nutrition Assistance Program (SNAP) in the past year, receipt of rental assistance, public health insurance coverage, and receipt of Supplemental Security Income (SSI), and are described in Table 10 below. The majority of families (17,214) in the sample are above the federal poverty line. There are 19.5% families reporting being below the poverty line, and 1,058, or 4.7%, are missing data. Utilization of SNAP in the last year is similarly reported to be "no" amongst 74.8% of the sample, with 24.9% being "yes" (57 sample respondents are missing). Rental assistance use includes a large portion of missing data, with 13,553 (59.8%) respondents missing. Rental assistance is reportedly used by 5.5% of the sample group, and not used by the remaining 34.7%. Public health insurance coverage is reported as not used by 59.2% of the sample while 40.3% report "yes" to any person in the home receiving Medicaid, other public assistance, a state sponsored plan or Children's Health Insurance Program (CHIP)

(106 families are missing data). The majority of the sample, 98.7%, did not report receiving income from Supplemental Security Income (SSI), with the remaining 1.7% reporting they did receive income from SSI, or are missing data (76 respondents).

Table 10. Socioeconomic indicators
(*N* = 22,697)

Socioeconomics	#	%
Poverty threshold		
Above	17,214	75.8
Below	4,425	19.5
Missing	1,058	4.7
SNAP in last year		
No	16,985	74.8
Yes	5,655	24.9
Missing	57	0.0
Rental Assistance		
No	7,886	34.7
Yes	1,258	5.5
Missing	13,553	59.8
Public health insurance coverage		
No	13,444	59.2
Yes	9,147	40.3
Missing	106	0.0
SSI		
No	22,324	98.7
Yes	297	1.3
Missing	76	0.0

Educational attainment. The educational attainment of the sample respondents is included in Table 11. The respondents answered for the highest education attained in the

Table 11. Educational attainment
(*N* = 22,697)

	#	%
Less than HS diploma	2,872	12.7
HS diploma	8,197	36.1
AA/Voc degree	2,903	12.8
Bachelor's	4,385	19.3
Master's or higher	3,421	15.1
Missing	919	4.0

household. Of these, 83.3% attained a high school diploma or higher, 12.7% attained less than a high school diploma, and 4% are missing data.

Review of research questions and hypotheses

The following section answers the research questions and discusses the hypotheses. Cohen's rules of thumb are used to characterize effect sizes as small, medium, or large (Cohen, 1988).

Research question one. What is the two year pooled prevalence rate of families with children with ASD?

The estimated prevalence of ASD based on pooled data from 2014 and 2015 was 2.25%, as shown in Table 12.

Table 12. Two year pooled ASD prevalence (2014 and 2015)

	Unweighted	**2-Yr Estimate**	**%**	SE
No ASD	22,208	128,261,468	97.8	0.001
ASD	489	2,947,678	2.25	0.001
Total	22,697	131,209,146	100.0	

Research question two. Do family structures of children with ASD differ from the general population?

It was hypothesized that there would be differences across family structures for families with children with ASD compared to families with children without an ASD diagnosis. This hypothesis was supported.

Table 13 shows the population estimates of different family structures for children with and without an autism diagnosis. These estimates utilize a margin of error of 95%, meaning that there is 95% confidence that the true population falls around the estimate, plus or minus the margin of error. As shown by the chi-squared test results, family structure is statistically different for people with and without ASD (χ^2 (1) = 91,636.46 $p < .001$).

Results show an estimated 19.0% of children with ASD live in single parent/adult family homes, compared to 16.8% of children without ASD. Most notably, this variation comes amongst children with ASD living with a single mother at a higher percent (16.0%, MOE = 0.042%) than children without the diagnosis (13.6%, MOE = 0.006%). Approximately 1.6% (MOE = 0.014%) of children with ASD live with a single father and 1.5% (MOE = 0.014%) live with some other single adult, whereas 2.3% (MOE = 0.003%) and 0.9% (MOE = 0.002%) of those without ASD live with a single or other single adult, respectively.

Table 13. Two year pooled population estimates of family structure by ASD diagnosis **(*N* = 22,674)**

Family Structure	No ASD (%)	95% Margin of error	ASD (%)	95% Margin of error	Total (%)
One Parent/Adult					
Mother	13.6	0.006	16.0	0.042	13.70
Father	2.3	0.003	1.6	0.014	2.30
Other single adult	0.9	0.002	1.5	0.014	0.90
Two Parents/Adults					
Married/unmarried	45.8	0.009	41.5	0.056	45.70
Parent & step parent	7.2	0.004	6.2	0.028	7.20
Parent & co-hab. partner	3.8	0.003	2.2	0.017	3.70
Parent & other adult	22.6	0.007	25.8	0.050	22.60
Other related and unrelated adults	3.8	0.003	5.3	0.026	3.80
	100.00		100.00		100.00

χ^2 (1) = 91,636.46 $p < .001$

The results show an estimated 75.7% of children with ASD live in a home with two parents/adults, compared to 79.4% of children without ASD. Children with ASD are shown to live with married/unmarried parents at a lower percent (41.5%, MOE = 0.056%) than children without the diagnosis (45.8%, MOE = 0.009%). Approximately 6.2% (MOE = 0.028%) of children with ASD live with a parent and step parent compared with 7.2% (MOE = 0.004%) of children without an ASD diagnosis. Results show 2.2% (MOE = 0.017%) of children with ASD live with a parent and cohabitating partner compared to 3.8% (MOE = 0.003%) of children without an ASD diagnosis. Results indicate 25.8% (MOE = 0.050) of children with ASD live with families structured with a parent and another adult while 22.6% (MOE = 0.007%) of children without the diagnosis are in the same arrangement. Children with an ASD diagnosis live with other related and

unrelated adults in 5.3% (MOE = 0.026%) of the sample while 3.8% (MOE = 0.003%) of children without the diagnosis live in the same arrangement.

Research question three. Does having a child with ASD relate to higher odds (likelihood) of specific family structures?

The hypothesis that children with ASD are less likely to live in two-parent households and more likely to reside in single mother households is supported.

Two Parent Household. Table 14 presents the sample distribution of single parent and two parent family structures by ASD status. Table 15 presents a logistic regression model that assesses the relationship of an ASD diagnosis and family structure.

Table 14. Distribution of ASD status by two-parent family structure

	No ASD		ASD		Total	
Single parent	4,886	22.0%	129	26.4%	5,015	22.1%
Two parents	17,322	78.0%	360	73.6%	17,682	77.9%
Total	22,208	100.0%	489	100.0%	22,697	100.0%

Specifically, this model seeks to understand the odds of a child with ASD residing in a two parent household, while controlling for different characteristics. Two parent households include those with married or unmarried parents, parents and step parents, parents and cohabitating partners, and parents and other adults.

The model was evaluated to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (10) = 2,474.134, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be

significant (χ^2 (8) = 17.577, $p < .025$), suggesting that the data did not fit the model well. However, a closer inspection of the related contingency table (see Table 15), suggests that significance of the goodness of fit test was likely a function of the large sample size due to a small deviation of the observed from the expected values of the two different family structure outcomes. This model correctly predicted 81.3% of the data.

Table 15. Two parent: contingency table for Hosmer and Lemeshow test

	Not two parents		Two parents		Total
	Observed	Expected	Observed	Expected	
1	1085	1102.022	1068	1050.978	2153
2	728	726.259	1349	1350.741	2077
3	585	564.118	1495	1515.882	2080
4	393	381.439	1532	1543.561	1925
5	315	323.126	1665	1656.874	1980
6	303	263.800	1797	1836.200	2100
7	158	161.297	1315	1311.703	1473
8	159	197.196	1989	1950.804	2148
9	113	111.051	1339	1340.949	1452
10	210	218.691	3198	3189.309	3408

Table 16 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .179. Controlling for demographics, socioeconomic factors, and the highest education in the household, children with ASD had 25% lower odds of living in a two parent household than children without ASD, as shown by the odds ratio (OR) of 0.749 ($p < .05$), with a 95% confidence interval ranging from 0.589 to 0.952. This is a small effect size. Also, there is a wide confidence interval, meaning there is potential that the true value is much smaller; or, actually larger.

The control variables were also found to be significantly related to children living in a two parent household. Compared to White children, those who are Black had 45%

lower odds (OR = 0.547, $p < .001$) and those of other races were found to have 1.67 higher odds ($p < .001$) of living with two parents. Those of Hispanic ethnicity also have significantly higher odds of living in a two parent household compared to those of other ethnicities (OR = 1.73, $p < .001$). Additionally, those in poverty had 56% lower odds (OR = 0.435, $p < .001$) of living in a two parent household than those above the poverty threshold, whereas those who own a home have 2.775 times higher odds than those who do not own a home ($p < .001$). Regarding education, those with a high school diploma or AA/Vocational degree had statistically equal odds of living in a two parent household as the reference group. Education beyond an AA/Vocational degree relates to increasingly higher odds of living in a two parent home, compared to the reference group.

Table 16. Logistic Regression: Two Parents (*N* = 20,796*)*

							95% C.I.for OR	
	B	S.E.	Wald	df	Sig.	OR	Lower	Upper
ASD	-0.289	0.123	5.556	1	0.018	0.749	0.589	0.952
Race								
White (ref.)			253.674	2	0.001			
Black	-0.604	0.048	159.257	1	0.001	0.547	0.498	0.600
Other	0.511	0.073	48.843	1	0.001	1.667	1.445	1.924
Ethnicity								
Hispanic	0.548	0.048	129.937	1	0.001	1.730	1.574	1.901
Below poverty	-0.833	0.045	343.900	1	0.001	0.435	0.398	0.475
Own home	1.021	0.042	579.422	1	0.001	2.775	2.554	3.016
Education								
No HS diploma (ref.)			88.527	4	0.001			
HS diploma	-0.049	0.058	0.729	1	0.393	0.952	0.850	1.066
AA/Vocational degree	0.116	0.074	2.456	1	0.117	1.123	0.971	1.298
Bachelor's degree	0.305	0.075	16.678	1	0.001	1.357	1.172	1.571
Master's degree or higher	0.548	0.086	40.853	1	0.001	1.730	1.463	2.047
Constant	0.966	0.066	213.003	1	0.001	2.627		

Nagelkerke *R2* = .179

Single Mother Household

Table 17 presents the distribution of ASD status by single mother family structure.

Table 17. Distribution of ASD status by single mother family structure

	No ASD		ASD		Total	
Single mother	3,214	14.5%	86	17.6%	3,300	14.6%
Other	18,971	85.5%	403	82.4%	19,374	85.4%
Total	22,185	100.0%	489	100.0%	22,674	100.0%

Table 19 presents a logistic regression model that assesses the relationship of an ASD diagnosis and living in a single-mother household, while controlling for different characteristics. The model was evaluated on the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (10) = 2,582.966, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be insignificant (χ^2 (8) = 10.014, $p < .264$), suggesting that the data did fit the model well, as confirmed by the contingency table show on Table 18. This model correctly predicted 85.0% of the data.

Table 18. Single Mother: contingency table for Hosmer and Lemeshow test

	Not single mother		Single mother		
	Observed	Expected	Observed	Expected	Total
1	1910	1914.974	83	78.026	1993
2	2688	2672.258	124	139.742	2812
3	2043	2028.446	117	131.554	2160
4	1152	1140.905	74	85.095	1226
5	1901	1905.587	160	155.413	2061
6	1837	1843.083	258	251.917	2095
7	1821	1848.049	349	321.951	2170
8	1633	1631.784	429	430.216	2062
9	1350	1369.283	628	608.717	1978
10	1218	1198.632	1001	1020.368	2219

Table 18 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .202. As can be seen, controlling for demographics, socioeconomic factors, and the mother's education, children with ASD had 1.389 higher odds, a small effect size, of living in a single-mother household than children without ASD ($p < .05$), with a 95% confidence interval ranging from 1.070 to 1.805.

Table 19. Logistic Regression: Single Mother

							95% C.I.for OR	
	B	S.E.	Wald	df	Sig.	OR	Lower	Upper
ASD	0.329	0.133	6.074	1	0.014	1.389	1.070	1.805
Race								
White (ref.)			292.260	2	0.001			
Black	0.739	0.051	209.599	1	0.001	2.094	1.894	2.314
Other	-0.474	0.082	33.729	1	0.001	0.623	0.531	0.731
Ethnicity								
Hispanic	-0.452	0.053	73.606	1	0.001	0.636	0.574	0.706
Below poverty	1.011	0.048	445.250	1	0.001	2.748	2.502	3.019
Own home	-1.182	0.048	601.235	1	0.001	0.307	0.279	0.337
Education								
No HS diploma			25.994	4	0.001			
HS diploma	0.048	0.062	0.595	1	0.440	1.049	0.929	1.186
AA/Vocational degree	0.001	0.080	0.001	1	0.991	1.001	0.855	1.172
Bachelor's degree	-0.141	0.082	2.957	1	0.086	0.868	0.739	1.020
Master's degree or higher	-0.330	0.095	12.062	1	0.001	0.719	0.597	0.866
Constant	-1.412	0.072	384.792	1	0.001	0.244		

Nagelkerke *R2* = .202

The control variables were also found to be related to children living in a single mother household. Compared to White children, Black children had 2.094 times higher odds ($p < .001$) and those of other races were found to have about 38% lower odds (OR = 0.623, $p < .001$) of living in a single mother household. Those of Hispanic ethnicity also had significantly lower odds compared to those of other ethnicities (OR = 0.623, $p < .001$) of living in a single mother household. Poverty appears to relate as well, with those experiencing poverty being 2.748 time more likely to live in single mother households than those not in poverty ($p < .001$). Those owning a house had 69% lower odds of living in a single mother household ($p < .001$). Regarding education, those with a high school diploma, AA/Vocational degree, or Bachelor's degree had statistically equal odds of living in a single mother household as the reference group. Those with Master's

degrees had 28% lower odds of living in a single mother home, compared to the reference group.

Research question four. What are the effects of ASD and family structures on public benefit usage?

There were two hypotheses related to this question. First, that two parent families with a child with ASD would have more public benefit usage than families with a child without and ASD diagnosis. Second, that one parent families with children with ASD would have more public benefit usage than families with children without an ASD diagnosis. Both of these hypotheses are supported by the findings from this study, and these findings are discussed below.

Supplemental Security Income (SSI).

Table 20 presents the distribution of ASD by family structure and SSI usage. Table 22 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .128. Results show, after controlling for demographics, socioeconomic factors, and the highest education in the household, children without ASD from single parent homes had 1.706 greater odds, a medium effect size, of using SSI in the last year, compared to those without ASD living in two parent households ($p < .001$). Of households with children with ASD from two parent and single parent homes, each had approximately 18 times higher odds, a large effect size, of using SSI in the last year compared to the reference group (both significant at the $p < .001$ level), while controlling for key variables.

Table 20. Distribution of ASD by family structure and SSI usage

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
No SSI	Count	17,143	4,757	316	108	22,324
	%	99.3%	97.8%	88.5%	84.4%	98.7%
SSI	Count	127	109	41	20	297
	%	0.7%	2.2%	11.5%	15.6%	1.3%
Total	Count	17,270	4,866	357	128	22,621
	%	100.0%	100.0%	100.0%	100.0%	100.0%

Table 22 presents a logistic regression model that assesses the relationship of family structure of children with and without autism diagnosis on the usage of Supplemental Security Income (SSI). Specifically, this model seeks to understand the odds for SSI usage of different family structures and autism, compared to those families whose children do not have an ASD diagnosis, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure. The reference groups is two parent families with children without an ASD diagnosis, and the comparison groups are no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

The model was evaluated to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (11) = 349.123, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be insignificant (χ^2 (8) = 14.743, $p < .064$), suggesting that the model did fit the data well. This is confirmed

by the related contingency table (see Table 21), showing observed values nearly identical to expected values. This model correctly predicted 98.8% of the data.

Table 21. SSI: contingency table for Hosmer and Lemeshow test

	Did not use SSI last year		Used SSI last year		
Step	Observed	Expected	Observed	Expected	Total
1	2390	2393.784	7	3.216	2397
2	1353	1351.998	2	3.002	1355
3	2156	2153.189	4	6.811	2160
4	2457	2458.751	14	12.249	2471
5	2154	2151.766	12	14.234	2166
6	2182	2182.555	19	18.445	2201
7	2594	2583.768	17	27.232	2611
8	2298	2303.935	39	33.065	2337
9	2097	2107.900	55	44.100	2152
10	1743	1736.354	98	104.646	1841

The control variables were also found to be related to SSI usage in the last year. Compared to White children, Black children were more likely to use SSI in the last year (OR = 1.561, ($p < .01$) while those of other races were found to have equal odds of SSI usage as the reference group. Those of Hispanic ethnicity also have significantly lower odds of SSI usage compared to those of other ethnicities (OR = 0.672, $p < .05$). Additionally, those who own a home have lower odds of using SSI in the last year (OR = 0.527, $p < .001$), after controlling for other variables. Regarding education, those with a high school diploma or AA/Vocational degree are found to have statistically equal odds of using SSI in the last year as the reference group. Education beyond an AA/Vocational degree relates to significantly lower odds of SSI usage, compared to the reference group.

Table 22. Logistic Regression: SSI Usage (*N* = 21,691)

							95% C.I.for EXP(B)	
	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			289.086	3	0			
No ASD - One Parent	0.534	0.15	12.619	1	0.001	1.706	1.271	2.292
ASD - Two Parents	2.908	0.194	224.509	1	0.001	18.313	12.519	26.788
ASD - One Parent	2.898	0.296	95.814	1	0.001	18.144	10.155	32.418
Race								
White (ref.)			13.415	2	0.001			
Black	0.445	0.152	8.563	1	0.003	1.561	1.158	2.104
Other	-0.460	0.285	2.601	1	0.107	0.631	0.361	1.104
Ethnicity								
Hispanic	-0.397	0.164	5.844	1	0.016	0.672	0.487	0.928
Education								
No HS Diploma (ref.)			36.518	4	0.001			
HS Diploma	-0.029	0.182	0.025	1	0.874	0.972	0.681	1.387
Associates/Vocational degree	-0.175	0.230	0.575	1	0.448	0.840	0.535	1.319
Bachelor's degree	-0.998	0.271	13.567	1	0.001	0.369	0.217	0.627
Master's degree or higher	-1.761	0.400	19.386	1	0.001	0.172	0.078	0.376
Home is owned	-0.641	0.147	18.995	1	0.001	0.527	0.395	0.703
Constant	-4.118	0.210	384.689	1	0.001	0.016		

Nagelkerke *R2* = .128

Supplemental Nutrition Assistance Program (SNAP).

Table 23 presents the distribution of ASD by family structure and SNAP usage. Table 25 presents a logistic regression model that assesses the relationship of family structure of children with and without autism diagnosis on the usage of Supplemental Nutrition Assistance Program (SNAP). Specifically, this model seeks to understand the odds of a different family structures and autism, compared to those without, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure, which included no ASD diagnosis and two parent household as the reference group, and the comparison groups as no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

Table 23. Distribution of ASD by family structure and SNAP usage

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
No SNAP	Count	13,823	2,813	274	75	16,985
	%	80.0%	57.8%	76.3%	58.1%	75.0%
SNAP	Count	3459	2057	85	54	5655
	%	20.0%	42.2%	23.7%	41.9%	25.0%
Total	Count	17,282	4,870	359	129	22,640
	%	100.0%	100.0%	100.0%	100.0%	100.0%

The model was evaluated on the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (12) = 5,398.261, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be significant (χ^2 (8) = 35.275, $p < .001$), suggesting that the model did not fit the data well.

Closer examination of the contingency table (see Table 24) shows moderate deviations between the observed and expected values, resulting in potential model misspecification. This model correctly predicted 78.1% of the data.

Table 24. SNAP: contingency table for Hosmer and Lemeshow test

	Did not received SNAP		Received SNAP		
Step	Observed	Expected	Observed	Expected	Total
1	2140	2123.304	17	33.696	2157
2	2672	2640.271	65	96.729	2737
3	1573	1592.076	114	94.924	1687
4	1928	1927.138	238	238.862	2166
5	1659	1674.282	334	318.718	1993
6	1616	1635.559	426	406.441	2042
7	1252	1287.128	530	494.872	1782
8	1434	1466.051	972	939.949	2406
9	1212	1167.521	1175	1219.479	2387
10	857	829.669	1446	1473.331	2303

Table 25 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .328. As can be seen, controlling for demographics, socioeconomic factors, and the highest education in the household, children without ASD from single parent homes had 1.715 greater odds, a medium effect size, of using SNAP in the last year, compared to the reference group, those without ASD living in two parent households ($p < .001$). Children with ASD from two parent homes had statistically equal odds as the reference group while those from single parent homes had over two times higher odds, a medium effect size, of using SNAP in the last year compared to the reference group, significant at $p < .01$ level.

The control variables were also found to be related to SNAP usage in the last year. Compared to White children, Black children are more likely to have used SNAP in

the last year (OR = 2.012, $p < .01$) and those of other races are found to have equal odds as the reference group. Those of Hispanic ethnicity also have slightly higher but significant odds compared to those of other ethnicities (OR = 1.100, $p < .05$). Additionally, those who own a home had significantly lower odds of using SNAP in the last year (OR = 0.310, $p < .001$) and those that used SSI in the last year had two times higher odds ($p < .001$), after controlling for other variables. As level of education increases the odds of utilizing SNAP decrease, compared to the reference group.

Table 25. Logistic Regression: SNAP (*N* = 21,660)

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			164.925	3	0.001			
No ASD - One Parent	0.539	0.043	158.215	1	0.001	1.715	1.577	1.865
ASD - Two Parents	0.261	0.147	3.138	1	0.076	1.298	0.973	1.732
ASD - One Parent	0.749	0.239	9.851	1	0.002	2.115	1.325	3.376
Race								
White (ref.)			211.924	2	0.001			
Black	0.699	0.048	208.712	1	0.001	2.012	1.830	2.212
Other	0.074	0.065	1.309	1	0.253	1.077	0.949	1.223
Ethnicity								
Hispanic	0.095	0.043	4.912	1	0.027	1.100	1.011	1.197
Education								
No HS Diploma (ref.)			1281.831	4	0.001			
HS Diploma	-0.547	0.049	122.343	1	0.001	0.579	0.525	0.638
Associates/Vocational degree	-1.062	0.065	266.182	1	0.001	0.346	0.304	0.393
Bachelor's degree	-2.094	0.075	779.325	1	0.001	0.123	0.106	0.143
Master's degree or higher	-3.035	0.118	657.100	1	0.001	0.048	0.038	0.061
Home is owned	-1.173	0.039	901.329	1	0.001	0.310	0.287	0.334
SSI in last year	0.710	0.142	24.843	1	0.001	2.033	1.538	2.687
Constant	0.052	0.057	0.816	1	0.366	1.053		

Nagelkerke *R2* = .328

Rental Assistance

Table 26 presents the distribution of ASD by family structure and rental assistance usage. Table 28 presents a logistic regression model that assesses the relationship of family structure of children with and without autism diagnosis on the usage of rental assistance. Specifically, this model seeks to understand the odds of different family structures and autism, compared to the those without, while controlling for different characteristics. The primary independent variable is ASD by family structure. The reference group are two parent families with children with no ASD diagnosis. The comparison groups include no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

Table 26. Distribution of ASD by family structure and rental assistance usage

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
No rental assistance	Count	5,559	2,190	97	40	7,886
	%	92.6%	73.8%	89.0%	60.6%	86.2%
Rental assistance	Count	443	777	12	26	1258
	%	7.4%	26.2%	11.0%	39.4%	13.8%
Total	Count	6,002	2,967	109	66	9,144
	%	100.0%	100.0%	100.0%	100.0%	100.0%

The model was evaluated to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (10) = 993.559, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be significant (χ^2 (8) = 15.538, $p < .049$), suggesting that the model did not fit the data well. Closer

examination of contingency table (see Table 27) shows minimal deviations between the observed and expected values, suggesting the significance of this test was likely a function of a highly powered analysis. This model correctly predicted 87.1% of the data.

Table 27. Rental Assistance: contingency table for Hosmer and Lemeshow test

	No rental assistance		Rental assistance		
Step 1	Observed	Expected	Observed	Expected	Total
1	836	841.207	17	11.793	853
2	813	817.274	38	33.726	851
3	1051	1057.682	66	59.318	1117
4	847	840.095	50	56.905	897
5	1000	976.885	55	78.115	1055
6	773	770.334	98	100.666	871
7	690	692.903	138	135.097	828
8	731	749.404	196	177.596	927
9	459	465.693	193	186.307	652
10	428	416.524	317	328.476	745

Table 28 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .197. As can be seen, controlling for demographics, and the highest education in the household, children without ASD from single parent homes had 3.643 greater odds, a medium effect size, of using rental assistance in the last year, compared to those without ASD living in two parent households ($p < .001$). Children with ASD from two parent homes had statistically equal odds as the reference group and those from single parent homes had over eight times higher odds, a high effect size, of using rental assistance in the last year compared to the reference group, significant at the $p < .001$ level.

The control variables were also found to be related to SNAP usage in the last year. Compared to White children, Black children and children of other races were three

and two times more likely, respectively, to use rental assistance in the last year, compared to the reference group. Those of Hispanic ethnicity had slightly lower odds (OR = 0.823, $p < .05$). Level of education had a negative relationship to rental assistance utilization, meaning, the odds were significant and decreased as education increased, compared to the reference group.

Table 28. Logistic Regression: Rental Assistance (N = 8,796)

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			369.026	3	0.001			
No ASD - One Parent	1.293	0.070	343.135	1	0.001	3.643	3.177	4.177
ASD - Two Parents	0.368	0.317	1.342	1	0.247	1.444	0.775	2.690
ASD - One Parent	2.152	0.290	54.872	1	0.001	8.599	4.866	15.194
Race								
White (ref.)			177.828	2	0.001			
Black	1.053	0.080	175.054	1	0.001	2.867	2.453	3.351
Other	0.696	0.116	35.919	1	0.001	2.006	1.597	2.519
Ethnicity								
Hispanic	-0.194	0.085	5.283	1	0.022	0.823	0.698	0.972
Education								
No HS Diploma (ref.)			147.276	4	0.001			
HS Diploma	-0.371	0.084	19.495	1	0.001	0.690	0.585	0.814
Associates/Vocational degree	-0.660	0.121	29.889	1	0.001	0.517	0.408	0.655
Bachelor's degree	-1.635	0.168	94.585	1	0.001	0.195	0.140	0.271
Master's degree or higher	-2.665	0.347	58.831	1	0.001	0.070	0.035	0.138
Constant	-2.314	0.102	511.565	1	0.001	0.099		

Nagelkerke *R2* = .197

Public Health Insurance Coverage

Table 29 presents the distribution of ASD by family structure and public health insurance usage. Table 31 presents a logistic regression model that assesses the

relationship of family structure of children with and without an autism diagnosis on their usage of public health insurance coverage. Public health insurance coverage here includes Medicaid, Children's Health Insurance Program, or some other state sponsored healthcare. Specifically, this model seeks to understand the odds of different family structures and autism, compared to those families without children with ASD, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure. The reference group is two parent families with children with no ASD diagnosis. The comparison groups include no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

Table 29. Distribution of ASD by family structure and public health insurance usage

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
No public health	Count	11,237	1,963	192	52	13,444
	%	65.2%	40.4%	53.3%	40.6%	59.5%
Public health	Count	6,008	2,895	168	76	9,147
	%	34.8%	59.6%	46.7%	59.4%	40.5%
Total	Count	17,245	4,858	360	128	22,591
	%	100.0%	100.0%	100.0%	100.0%	100.0%

The model was evaluated on the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (12) = 7,117.490, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be significant (χ^2 (8) = 46.090, $p < .001$), suggesting that the model did not fit the data well. Closer examination of the contingency table (see Table 30) shows moderate deviations

between the observed and expected values, resulting in potential model misspecification. This model correctly predicted 75.0% of the data.

Table 30. Public Health Insurance : contingency table for Hosmer and Lemeshow test

	No Health Insurance		Health Insurance		
Step 1	Observed	Expected	Observed	Expected	Total
1	2085	2052.440	71	103.560	2156
2	2481	2442.570	201	239.430	2682
3	2092	2091.334	388	388.666	2480
4	1111	1129.511	400	381.489	1511
5	1384	1424.327	681	640.673	2065
6	1256	1303.789	961	913.211	2217
7	914	951.683	1130	1092.317	2044
8	864	885.222	1665	1643.778	2529
9	584	543.385	1518	1558.615	2102
10	339	285.740	1495	1548.260	1834

Table 31 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .380. Controlling for demographics, socioeconomic factors, and the highest education in the household, children without ASD from single parent homes had 1.440 greater odds, a small effect size, of using public health insurance in the last year, compared to those without ASD living in two parent households ($p < .001$). Children with ASD from two parent and single parent homes had approximately 2 times, a small effect size, higher odds of using public health insurance in the last year, compared to the reference group ($p < .001$ and $p < .01$, respectively), while controlling for key variables.

The control variables were also found to be significantly related to public health insurance usage in the last year. Compared to White children, those children who are Black (OR = 1.824, $p < .001$) and other races (OR = 1.302, $p < .001$) were significantly more likely to use public health insurance in the last year. Those of Hispanic ethnicity

also have significantly higher odds of using public health insurance compared to those of other ethnicities (OR = 1.724, $p < .001$). Additionally, home ownership resulted in significantly lower odds of using public health insurance in the last year (OR = 0.320, $p < .001$) and those that used SSI in the last year had nearly three time higher odds ($p < .001$), after controlling for other variables. As level of education increases, the odds of utilizing public health insurance decrease, compared to the reference group.

Table 31. Logistic Regression – Public Health Insurance Usage

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			104.336	3	0.001			
No ASD - One Parent	0.365	0.043	72.662	1	0.001	1.440	1.324	1.566
ASD - Two Parents	0.714	0.132	29.423	1	0.001	2.041	1.577	2.642
ASD - One Parent	0.766	0.245	9.767	1	0.002	2.151	1.330	3.476
Race								
White (ref.)			167.606	2	0.001			
Black	0.601	0.047	162.301	1	0.001	1.824	1.663	2.001
Other	0.264	0.057	21.244	1	0.001	1.302	1.164	1.457
Ethnicity								
Hispanic	0.545	0.039	193.025	1	0.001	1.724	1.597	1.862
Education								
No HS Diploma (ref.)			2090.583	4	0.001			
HS Diploma	-0.720	0.053	184.950	1	0.001	0.487	0.439	0.540
Associates/Vocational degree	-1.380	0.064	471.113	1	0.001	0.252	0.222	0.285
Bachelor's degree	-2.166	0.065	1113.503	1	0.001	0.115	0.101	0.130
Master's degree or higher	-2.921	0.083	1240.916	1	0.001	0.054	0.046	0.063
Home is owned	-1.072	0.035	956.235	1	0.001	0.342	0.320	0.366
SSI in last year	1.375	0.174	62.629	1	0.001	3.956	2.814	5.561
Constant	0.956	0.059	262.695	1	0.001	2.602		

Nagelkerke *R2* = .380

Research question five. What are the effects of ASD and family structure on parental educational attainment?

Two hypotheses were generated related to this question. First, it was hypothesized that two parent families with a child with ASD would have higher educational attainment than two parent families with children without the diagnosis. Second, it was hypothesized that one parent families with children with ASD would have lower educational attainment than two parent families with children with no ASD

diagnosis. Neither of these hypotheses were supported by the findings, which are discussed below.

High School Diploma or Less

Table 32 presents the distribution of ASD by family structure and parental educational attainment of a high school diploma or less. Table 34 presents a logistic regression model that assesses the relationship of family structure ofchildren with and without autism diagnosis on the likelihood of the highest education in the family being a high school (HS) diploma or less. Specifically, this model seeks to understand the odds of a different family structures and autism, compared to the those without, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure. The reference group is two parent households with children with no ASD diagnosis. The comparison groups include no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

Table 32. Distribution of ASD by family structure and high school diploma or less

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
Higher than HS	Count	9,117	1,351	191	50	10,709
	%	52.8%	33.4%	53.1%	47.2%	49.2%
HS or less	Count	8,152	2,692	169	56	11,069
	%	47.2%	66.6%	46.9%	52.8%	50.8%
Total	Count	17,269	4,043	360	106	21,778
	%	100.0%	100.0%	100.0%	100.0%	100.0%

The model was evaluated at the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (8) = 4,643.886, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be significant (χ^2 (7) = 83.524, $p < .001$), suggesting that the model did not fit the data well. Closer examination of contingency table (see Table 33) shows moderate deviations between the observed and expected values, resulting in potential model misspecification. This model correctly predicted 70.7% of the data.

Table 33. High School (HS) or Less - Contingency Table for Hosmer and Lemeshow Test

	Higher than HS		HS diploma or less		
Step 1	Observed	Expected	Observed	Expected	Total
1	707	709.539	213	210.461	920
2	4642	4476.159	1560	1725.841	6202
3	1282	1309.110	748	720.890	2030
4	966	1013.748	922	874.252	1888
5	500	546.715	701	654.285	1201
6	796	893.270	1287	1189.730	2083
7	704	749.575	1844	1798.425	2548
8	419	371.158	1500	1547.842	1919
9	231	177.725	1774	1827.275	2005

Table 32 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .267. As can be seen, controlling for demographics, and socioeconomic factors, children without ASD from single parent homes had 1.407 greater odds, a small effect size, of living in home with the highest education level being a HS diploma or less, compared to those without ASD living in two parent households ($p < .001$). Children with ASD from single and two parent homes had statistically equal odds of HS or less, compared to the reference group.

The control variables were also found to be significantly related. Compared to White children, those who are Black were significantly more likely to reside in home with the highest education being HS or less (OR = 1.402, $p < .001$) and those of other races were found to have significantly lower odds as the reference group (OR = 0.767, $p < .001$). Those of Hispanic ethnicity were significantly more likely to live in a home with the highest education being a HS diploma or less (OR = 3.393, $p < .001$). Additionally, those who owned a home had significantly lower odds (OR = 0.453, $p < .001$) and those in poverty had significantly higher odds (OR = 3.929, $p < .001$), after controlling for other variables.

Table 34. Logistic Regression - HS diploma or less (*N* = 20,796)

							95% C.I.for EXP(B)	
	B	S.E.	Wald	Df	Sig.	Exp(B)	Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			63.840	3	0.001			
No ASD - One Parent	0.342	0.043	62.681	1	0.001	1.407	1.293	1.532
ASD - Two Parents	0.056	0.121	0.213	1	0.645	1.057	0.835	1.339
ASD - One Parent	-0.160	0.224	0.510	1	0.475	0.852	0.550	1.321
Race								
White (ref.)			95.866	2	0.001			
Black	0.338	0.046	54.435	1	0.001	1.402	1.282	1.534
Other	-0.266	0.053	25.211	1	0.001	0.767	0.691	0.850
Ethnicity								
Hispanic	1.222	0.037	1079.814	1	0.001	3.393	3.155	3.650
Home is owned	-0.792	0.034	544.991	1	0.001	0.453	0.424	0.484
Below Poverty	1.368	0.048	823.031	1	0.001	3.929	3.579	4.314
Constant	-0.161	0.034	21.809	1	0.001	0.851		

Nagelkerke *R2* = .267

Associates or Vocational Degree

Table 35 presents the distribution of ASD by family structure and highest parental attainment of an associate or vocational degree.

Table 35. Distribution of ASD by family structure and Associate or Vocational degree

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
No AA/Voc	Count	14,948	3,522	316	89	18,875
	%	86.6%	87.1%	87.8%	84.0%	86.7%
AA/Voc degree	Count	2,321	521	44	17	2,903
	%	13.4%	12.9%	12.2%	16.0%	13.3%
Total	Count	17,269	4,043	360	106	21,778
	%	100.0%	100.0%	100.0%	100.0%	100.0%

Table 37 presents a logistic regression model that assesses the relationship of family structure ofchildren with and without autism diagnosis on the likelihood of the highest education in the family being an associates (AA) or vocational degree. Specifically, this model seeks to understand the odds of a different family structures and autism, compared to those without, while controlling for different characteristics. The primary independent variable was ASD by family structure, which includes no ASD diagnosis and two parent household as the reference group, and the comparison groups as no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

The model was evaluated on the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (8) = 128.543, $p < .001$).

Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be insignificant (χ^2 (6) = 9.226, p = .161), suggesting that the model did fit the data well. Confirmation can be found on the contingency table (see Table 36) showing minimal deviations between the observed and expected values. This model correctly predicted 86.6% of the data.

Table 36. Associates (AA) or Vocational (Voc) Degree - Contingency Table for Hosmer and Lemeshow Test

Step 1	No AA/Voc degree		AA/Voc degree		
	Observed	Expected	Observed	Expected	Total
1	1912	1889.106	147	169.894	2059
2	2218	2240.934	292	269.066	2510
3	1298	1287.209	159	169.791	1457
4	1886	1904.228	279	260.772	2165
5	2066	2058.115	314	321.885	2380
6	5270	5254.321	932	947.679	6202
7	1195	1193.117	224	225.883	1419
8	2157	2174.970	447	429.030	2604

Table 37 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .011. As shown, controlling for demographics, and socioeconomic factors, the odds for the highest education in the household being an AA or vocational degree did not statistically differ between the reference group and different family structures with and without ASD.

There were differences with the control variables. Compared to White children, those who are Black did not statistically differ, however those of other races were significantly less likely to have an AA or vocational degree as the highest education in the household (OR = 0.697, p < .001). Those of Hispanic ethnicity were significantly less likely to live in a home with the highest education being an AA or vocational degree

(OR = 0.752, $p < .001$). Additionally, those who owned a home had statistically equal odds as those that did not and those in poverty had significantly lower odds (OR = 0.646, $p < .001$), after controlling for other variables.

Table 37. Logistic Regression - Associate's or Vocational Degree (N = 20,796)

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			1.142	3	0.767			
No ASD - One Parent	-0.007	0.056	0.015	1	0.903	0.993	0.890	1.109
ASD - Two Parents	-0.086	0.164	0.276	1	0.599	0.918	0.666	1.264
ASD - One Parent	0.244	0.268	0.835	1	0.361	1.277	0.756	2.157
Race								
White (ref.)			24.654	2	0.001			
Black	0.042	0.059	0.501	1	0.479	1.043	0.929	1.171
Other	-0.361	0.076	22.478	1	0.001	0.697	0.600	0.809
Ethnicity								
Hispanic	-0.285	0.051	31.750	1	0.001	0.752	0.681	0.830
Home is owned	-0.069	0.046	2.205	1	0.138	0.934	0.853	1.022
Below Poverty	-0.436	0.061	50.464	1	0.001	0.646	0.573	0.729
Constant	-1.644	0.047	1249.820	1	0.001	0.193		

Nagelkerke $R2$ = .011

Bachelor's Degree or Higher

Table 38 presents the distribution ASD by family structure and parental attainment of a Bachelor's degree of higher. Table 40 presents a logistic regression model that assesses the relationship of family structure ofchildren with and without autism diagnosis on the likelihood of the highest education in the family being a Bachelor's degree or higher. Specifically, this model seeks to understand the odds of different family structures and autism, compared to those families without children with

ASD, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure, which included children with no ASD diagnosis and two parent household as the reference group, and the comparison groups as no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

Table 38. Distribution of ASD by family structure and Bachelor's degree or higher

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
Lower than BA	Count	10473	3213	213	73	13972
	%	60.6%	79.5%	59.2%	68.9%	64.2%
BA or higher	Count	6796	830	147	33	7806
	%	39.4%	20.5%	40.8%	31.1%	35.8%
Total	Count	17269	4043	360	106	21778
	%	100.0%	100.0%	100.0%	100.0%	100.0%

The model was evaluated at the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (8) = 4,642.061, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be significant (χ^2 (6) = 23.789, $p < .001$), suggesting that the model did not fit the data well. Closer examination of contingency table (see Table 39) shows moderate deviations between the observed and expected values, resulting in potential model misspecification. This model correctly predicted 71.8% of the data.

Table 39. Bachelor's Degree - contingency table for Hosmer and Lemeshow test

Step 1	No Bachelor's degree	Bachelor's degree	Total

	Observed	Expected	Observed	Expected	
1	1925	1943.375	80	61.625	2005
2	1734	1757.792	179	155.208	1913
3	1649	1633.104	253	268.896	1902
4	1588	1582.271	505	510.729	2093
5	1435	1391.978	509	552.022	1944
6	1406	1385.602	846	866.398	2252
7	798	760.308	712	749.692	1510
8	2808	2888.571	4369	4288.429	7177

Table 40 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .274. As can be seen, controlling for demographics, and socioeconomic factors, the odds for the highest education in the household being a Bachelor's degree or higher did not statistically differ for the single and two parent homes for kids with ASD, compared to the reference group. However, single parent families without a child with ASD had lower odds, with a small effect size (OR = 0.668, $p < .001$).

The control variables were also found to be significantly related to education in the home. Compared to White children, Black children were significantly less likely to reside in homes where the highest education attained is a Bachelor's degree or higher (OR =0.682, $p < .001$) and those of other races were found to have higher odds compared to the reference group (OR = 1.617, $p < .001$). Those of Hispanic ethnicity were less likely to live in a home with the highest education being a Bachelor's degree or higher (OR = 0.281, $p < .001$). Additionally, those who owned a home had higher odds (OR = 2.521, $p < .001$) and those in poverty had lower odds (OR = 0.186, $p < .001$), after controlling for other variables.

Table 40. Logistic Regression - Bachelor's Degree or Higher (N = 20,796)

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			69.882	3	0.001			
No ASD - One Parent	-0.404	0.048	69.568	1	0.001	0.668	0.608	0.734
ASD - Two Parents	-0.005	0.122	0.002	1	0.968	0.995	0.784	1.263
ASD - One Parent	0.020	0.239	0.007	1	0.932	1.021	0.639	1.630
Race								
White (ref.)			168.325	2	0.001			
Black	-0.383	0.050	58.056	1	0.001	0.682	0.618	0.753
Other	0.481	0.053	82.522	1	0.001	1.617	1.458	1.794
Ethnicity								
Hispanic	-1.271	0.042	894.549	1	0.001	0.281	0.258	0.305
Home is owned	0.925	0.037	624.599	1	0.001	2.521	2.345	2.711
Below Poverty	-1.681	0.065	667.416	1	0.001	0.186	0.164	0.212
Constant	-0.587	0.037	247.883	1	0.001	0.556		

Nagelkerke *R2* = .274

Research question six. What are the effects of ASD and family structure on household income?

Two hypotheses were generated in relation to this question. First, that two parent families with children with an ASD diagnosis will have higher income than two parent families with children without an ASD diagnosis. This hypothesis was not supported by the findings. Second, that one parent families with children with ASD will have lower income than two parent families without an ASD diagnosis. This hypothesis was supported by the findings. Results are displayed below.

Table 41 presents the distribution of ASD by family structure and household income. Table 43 presents a logistic regression model that assesses the relationship of family structure of children with and without an autism diagnosis on the likelihood of having a household income below $50,000. Specifically, this model seeks to understand the odds of this outcome for different family structures and autism, compared to those without children with ASD, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure, which included no ASD diagnosis and two parent household as the reference group, and the comparison groups as no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

Table 41. Distribution of ASD by family structure and household income

		No ASD - Two Parents	No ASD - One Parent	ASD - Two Parents	ASD - One Parent	Total
Above $50,000	Count	9902	1136	193	35	11266
	%	62.1%	24.2%	57.1%	27.8%	53.4%
Below $50,000	Count	6049	3552	145	91	9837
	%	37.9%	75.8%	42.9%	72.2%	46.6%
Total	Count	15951	4688	338	126	21103
	%	100.0%	100.0%	100.0%	100.0%	100.0%

Table 43 presents a logistic regression model that assesses the relationship of family structure ofchildren with and without autism diagnosis on the likelihood of a household income below $50,000. Specifically, this model seeks to understand the odds of a different family structures and autism, compared to the those without, while controlling for different characteristics. In this case, the primary independent variable was ASD by family structure, which included no ASD diagnosis and two parent

household as the reference group, and the comparison groups as no ASD and single parent household, ASD and two parent household, and ASD and single parent household.

The model was evaluated on the outset to ensure key assumptions were met. First, the results of the omnibus test of model coefficients show that the independent variables do significantly relate to the dependent variable (χ^2 (12) = 8,885.814, $p < .001$). Additionally, the Hosmer and Lemeshow model goodness of fit test was found to be significant (χ^2 (8) = 24.493, $p < .01$), suggesting that the model did not fit the data well. Closer examination of contingency table (see Table 42) shows minor deviations between the observed and expected values, suggesting the significance of the test is, at least in part, a function of the power of the large dataset. This model correctly predicted 77.7% of the data.

Table 42. Income: contingency table for Hosmer and Lemeshow test

	At or above $50,000		Below $50,000		
Step 1	Observed	Expected	Observed	Expected	Total
1	1796	1776.640	61	80.360	1857
2	1994	1963.893	151	181.107	2145
3	1466	1486.258	270	249.742	1736
4	1209	1205.871	360	363.129	1569
5	1441	1484.416	782	738.584	2223
6	1175	1173.103	944	945.897	2119
7	809	835.586	1409	1382.414	2218
8	498	514.565	1589	1572.435	2087
9	416	384.859	1902	1933.141	2318
10	169	147.810	1819	1840.190	1988

Table 43 presents the results of the logistic regression model. The Nagelkerke R^2 was found to be .505. As shown, controlling for demographics, education, and socioeconomic factors, all family structures with and without children with ASD were

significantly more likely to have a household income below $50,000 compared to the reference group. The odds ranged from 1.581 for two-parent homes of kids with ASD to 2.080 for single parent homes for kids with ASD, both small effect sizes.

The control variables were also found to be significantly related to household income. Compared to White children, Black children were significantly more likely to reside in homes with a household income under $50,000 (OR =1.878, $p < .001$) and those of other races were found to not significantly differ. Those of Hispanic ethnicity were more likely to live in a home with lower income (OR = 1.466, $p < .001$). All levels of education related to lower odds of residing in a household with an income below $50,000, compared to those with no HS diploma. Additionally, those who owned a home had lower odds (OR = 0.205, $p < .001$) and those on SSI had higher odds (OR = 4.998, $p < .001$), after controlling for other variables.

Table 43. Logistic Regression - Household Income Below $50,000 (*N* = 20,260)

							95% C.I.for EXP(B)	
	B	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Autism & Family Structure								
No ASD - Two Parents (ref.)			181.034	3	0.001			
No ASD - One Parent	0.483	0.037	171.245	1	0.001	1.621	1.508	1.743
ASD - Two Parents	0.458	0.181	6.395	1	0.011	1.581	1.109	2.256
ASD - One Parent	0.732	0.176	17.289	1	0.001	2.080	1.473	2.938
Race								
White (ref.)			143.152	2	0.001			
Black	0.630	0.053	143.032	1	0.001	1.878	1.694	2.083
Other	0.111	0.062	3.249	1	0.071	1.118	0.990	1.261
Ethnicity								
Hispanic	0.382	0.043	80.661	1	0.001	1.466	1.349	1.594
Education								
No HS Diploma (ref.)			2197.060	4	0.001			
HS Diploma	-1.055	0.065	264.485	1	0.001	0.348	0.307	0.395
Associates/Vocational degree	-1.641	0.074	491.882	1	0.001	0.194	0.168	0.224
Bachelor's degree	-2.533	0.074	1160.200	1	0.001	0.079	0.069	0.092
Master's degree or higher	-3.385	0.091	1388.349	1	0.001	0.034	0.028	0.040
Home is owned	-1.587	0.037	1863.930	1	0.001	0.205	0.190	0.220
SSI in last year	1.609	0.206	60.900	1	0.001	4.998	3.337	7.487
Constant	1.814	0.073	625.640	1	0.001	6.134		

Nagelkerke *R2* = .505

Chapter VI: Discussion and Implications

The aim of this study is to understand the relationships between family characteristics of those families with children with ASD. Previous literature has mainly focused on individuals with ASD, and the literature on family experiences has relied on relatively small datasets or qualitative inquiry. NHIS represents the most in-depth health survey conducted in the United States, with more than 12,000 sample child interviews completed annually. In person interviews and strong response rates make NHIS the principal source of information on the non-institutionalized population of the United States (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Understanding the family experience of families with children with ASD using a large, nationally-representative dataset fills an important gap in the knowledge base around this population. The following chapter includes a discussion of the findings; policy implications, limitations of the study, and directions for future research are considered.

Discussion of findings

The findings from this study offer increased insight in to the family structures and socioeconomic factors of families with children with ASD. A number of variables were used to explore these associations, and they are discussed below.

Prevalence estimate. Using pooled data from 2014 and 2015 (offering a more stable estimate), this study provides an estimated prevalence of children with autism spectrum disorder of 2.25%. This rate is consistent with the single year estimates from the 2014 and 2015 NHIS data (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). The most recent ADDM prevalence of children with ASD in the United States estimate is 1.47% (Christensen, et al., 2016). It is important to note that the ADDM selects sites in

which to complete prevalence estimates using a competitive grant process, and is not a randomly selected population sample (the most recent estimate is based on data reported from 11 sites), and does not represent the entire population of children living in the United States.

Previous research suggests autism prevalence estimates are likely underestimated, in particular because of the underestimated prevalence in lower SES groups (Rice, et al., 2012), and this study may do so as well. The ADDM relies on data from children who are receiving some type of service, either in an educational or medical setting. The NHIS estimate of one in 45 children does not replace the ADDM estimate of 1 in 68 children because the NHIS relies on parent report, but does lend credence to the idea that ASD is underestimated. In addition to the ADDM prevalence estimate of 1.47%, studies in Asian, Europe, and North America, using a number of different methods, have identified individuals with ASD with an average prevalence of between 1% and 2% (Centers for Disease Control and Prevention, 2016).

It is important to emphasize that estimating prevalence of ASD is challenging in a number of ways, including the nature of the condition itself, the diagnostic procedures, and accessibility issues faced by families in attaining a diagnosis.

Family structures. This study compares the distribution of the general population and ASD across family structure, providing the likelihood of being in different family structures. Previous research has using NHIS data has shared the prevalence rate of family structure for families with children with ASD. The previously reported prevalence rate for children in two parent households is 2.25%, 2.21% for single parent households, and 2.44% for other (Zablotsky, Black, Maenner, Schieve, & Blumberg,

2015). This study enhances the understanding by accounting for where children with ASD reside by showing the distribution across different family structures rather than the prevalence of ASD by family structure. This study shows that of children with ASD, approximately 76% live in two parent households while nearly 80% of children without ASD reside in these same situations. Additionally, after controlling for other variables, children with ASD had significantly lower odds of living in a two parent home than children without ASD. Another study examining this issue using a large epidemiological dataset found no difference in the odds of children with ASD living in a household not comprised of their two parents (Freedman, Kalb, Zablotsky, & Stuart, 2012). That study utilized data from the 2007 National Survey of Children's Health, a nationally representative sample. There are a number of possible reasons for this difference in finding, including survey design (the NSCH is a telephone survey), survey year (the study using the NSCH uses one year of data, from 2007), and definition and collection of information on autism. Diagnostic issues may play a role as well, as increasing education and awareness of autism impacts the population.

Two parent households in this study include those children living in a home with a biological or adoptive parent and another related adult. This grouping accounted for 26% of the sample. The potential assistance that related adults provide in terms of caregiving and finances may be an important resource to families that would otherwise exist in single parent households. Of course, these related adults may be non-contributory, however, it is plausible that these related adults do provide an important resource to families who would otherwise be parenting alone.

This study finds that children with ASD are 1.39 times more likely to reside with a single mother than children without ASD. A focus on the comparison in family structure of single mothers is important given what is known about the experiences of single mothers, and about mothers of children with ASD. Women have long faced inequality across many spectrums, including in accessing the labor market, and in earnings (Katz, Stern, & Fader, 2005). Research on psychological functioning in parents with ASD has indicated that mothers in general experience greater levels of stress than fathers (Hastings, et al., 2005). Additional research describing stress in mothers of children with ASD indicates that those feelings and experiences of stress are compounded when the mother is a single parent (Bromley & Hare, 2004). Mothers are more likely to experience financial declines as a result of divorce (Teachman & Paasch, 1994). Mother's in high income and low income situations tend to experience more stress than mothers in intermediate income situations, (with low income exhibiting the most stress) possibly due to the pressures of work and career (high income) and the known effect of financial hardship on stress (low income); in both groups, access to differing outside resources were important in mitigating stress (daycare, family, friends) (Parkes, Sweeting, & Wight, 2015). Additionally, though single mothers are more likely to be reliant on a personal safety net (that is, resources from friends and family to assist in meeting the needs of their family, economic and otherwise), they are less likely to have access to dependable and consistent resources to help in times of need (Harknett & Hartnett, 2011) (Kalil & Ryan, 2010).

Relationships of ASD by family structure and socioeconomics. Population indicators of socioeconomic status, such as those considered in this study (household

wealth, income, parental education), among others, are strongly correlated with the health and development of children (Durkin, et al., 2010). This study considers the impact of these indicators on the family unit and contributes to the previous body of research which has described the ways in which these indicators of SES impact the family unit as a whole, and in particular, families with children with ASD.

Unlike other disabilities, where population prevalence decreases as SES increases, evidence for ASD and associations with SES has been mixed and more often in the inverse of other developmental disabilities (Durkin, et al., 2010). There are studies which have found positive associations with parental education and income and ASD (Durkin, et al., 2010) (Finnegan & Quarrington, 1979) (Cox, Rutter, Newman, & Burtak, 1975), while others have failed to find an association between ASD and SES (Maenner, Arneson, & Durkin, 2009) (Bhasin & Schendel, 2007), with one case-control study finding lower educational attainment among mothers of children with ASD compared to controls (Burd, Severud, Kerbeshian, & Klug, 1999). In addition to some of the studies being outdated, and therefore operating from a previous definition of autism, research in this topic has recently relied primarily on data from one source, the ADDM Network, rather a nationally representative sample. Some researchers have argued that the associations between SES and ASD can be attributed to ascertainment bias as parents with higher SES have the information and resources to access specialized services (Tsai, Stewart, Faust, & Shook, 1982); essentially, that as parental wealth and education increase, so will the chances that a child with ASD will receive an informed diagnosis (Wing, 1980). Durkin et al (2010) examined this by utilizing ADDM Network data and comparing children with pre-existing ASD diagnoses and those without an ASD

diagnosis. The researchers used census block data and compared SES factors, including poverty, median household income, and attainment of a bachelor's degree. The authors found that children with ASD overall had higher SES, regardless of if they had a pre-existing diagnosis in their record, though those with a pre-existing diagnosis had higher gradients of association (it is important to note that ADDM data is collected on children who have had some interaction with the service system, either in a health or educational setting). The only group the effect was not observed in was those children with co-occurring autism and intellectual disability with the authors positing this may be explained by ascertainment bias (more evaluations are done on children with intellectual disability) or because intellectual disability among children is inversely associated with SES (Durkin, et al., 2010).

Tables 44 and 45 provide summary results from this study on education and income as related to family structures and autism.

Table 44. Odds Ratio of Education Models

	HS diploma or less		Associate's or vocational		Bachelor's or higher	
	OR	Sig.	OR	Sig.	OR	Sig.
Autism & Family Structure						
No ASD - Two Parents (ref.)	-		-		-	
No ASD - One Parent	1.407	***	0.993	NS	0.668	***
ASD - Two Parents	1.057	NS	0.918	NS	0.995	NS
ASD - One Parent	0.852	NS	1.277	NS	1.021	NS

Table 45. Odds Ratio of Income Model

	Income below $50,000	
	OR	Sig.
Autism & Family Structure		
No ASD - Two Parents (ref.)	-	
No ASD - One Parent	1.621	*
ASD - Two Parents	1.581	***
ASD - One Parent	2.080	***

Notably, after controlling for key variables, the highest education of one and two-parent households with children with ASD did not differ from the reference group. They did, however, differ from the reference group with respect to income below $50,000. Two parent households with a child with ASD were 1.6 times more likely to have an income below this threshold, whereas one parent households with a child with ASD were two times more likely. These findings contribute to the knowledge base on ASD and socioeconomic indicators by providing results from a large, nationally-representative sample. They also specify outcomes by family arrangement, allowing for more nuanced comparisons. These results contradict the picture of families with children with ASD as existing in families with higher income and education attainment as compared to the general population.

Table 46 provides a summary of the odds of public benefit usage for families with children with ASD by family structure. Investigating public benefit usage for SSI, SNAP, rental assistance (family pays lower rent because federal, state, or local government pays part of cost), and healthcare (Medicaid, Children's Health Insurance

Program, or some other state sponsored healthcare) offers a view of the supports different families are accessing.

Table 46. Odds Ratio of Benefit Usage Models

	Model							
	SSI		SNAP		Rental Assistance		Health	
	OR	Sig	OR	Sig	OR	Sig	OR	Sig
Autism & Family Structure								
No ASD - Two Parents (ref.)	-		-		-		-	
No ASD - One Parent	1.706	***	1.715	***	3.643	***	1.440	***
ASD - Two Parents	18.313	***	1.298	NS	1.444	NS	2.041	***
ASD - One Parent	18.144	***	2.115	**	8.599	***	2.151	**

As shown in Table 46, families with ASD, whether two parents or one parent, are more likely to engage with the service system through use of public benefits. SSI provides a basic monthly income guarantee to children and adults with disabilities as well as to people aged 65 and older. It is designed to help with meet basic needs for food, clothing, and shelter for people with little or no income. Eligibility requirements include: being age 65, or having a qualifying disability or being deemed blind; meeting income requirements; and having resources below a certain limit (Social Security Administration, 2016). Due to eligibility factors including disability, it is not surprising that SSI usage was greater among this population; the results do provide insights in to usage by different family types.

Supplemental Security Income (SSI) is a means-tested program that provides monthly income support to eligible persons who are aged, blind, or disabled. Unlike SNAP benefits, which can only be used to purchase food, SSI recipients can use these funds as needed, including food insecurity. There are high levels of cross-participation

between SSI, and SNAP and Medicaid; in most states, SSI recipients are automatically eligible to receive SNAP (Houtenville & Brucker, 2014; Trentkamp & Wiseman, 2007). In most states, qualifying for SSI also means qualifying for Medicaid and in many cases for housing benefits (Social Security Administration, 2016). This study controlled for SSI usage to better isolate the effects of ASD and family structure, while accounting for the confounding benefit relationship.

SNAP, the cornerstone of federal food assistance programs, provides monthly benefits to families meeting resource and income guidelines (these must be met unless all members are receiving SSI). Households are eligible for SNAP if they meet three criteria: 1) their gross monthly income must be less than 130 percent of the federal poverty level (some states use a cutoff above this); 2) the net monthly income must be below the federal poverty level; and, 3) assets must be less than $2,000. Households with elderly and disabled people are allowed, for example, a medical cost deduction and are also allowed more assets. SNAP has been shown to alleviate food insecurity and reduce poverty, though for many recipients, the benefit is not enough to remove them from food insecurity (Gundersen & Ziliak, 2015). Food security means having constant access to enough food for a healthy and active life (United States Department of Agriculture Economic Research Service, 2016).

The United States Department of Agriculture reports an estimated 12.7% of households were food insecure in 2015, down from 14.0% in 2014. This means these families had difficulty at some point during the year providing enough food for all their family members due to lack of resources (5.0 in 2015 and 5.6% in 2014 were in the more severe range of *very low food security*). Children were food insecure in 7.8% and 9.4%

(2015 and 2014, respectively) of households with children, meaning there were times during the year in which these households were unable to provide adequate, nutritious food for their children. Significantly, in households with children, food insecurity was higher in single female-headed households (14.9%) and in low-income households with incomes below 185% of the poverty line (17.5%) (Coleman-Jensen, Rabbitt, Gregory, & Singh, 2016).

Previous research has shown both food insecurity and SNAP use to be prevalent among low-income households, and, compared to non-SNAP recipient households, recipient households tend to be younger, minority, less educated, headed by a female, to have more children, and to include a member with a disability (Ratcliffe, McKernan, & Zhang, 2011). The findings here are consistent with previous research showing a number of demographic characteristics to be important determinants of food insecurity. This study found no difference in use of SNAP benefits between families with two parents, whether there was a child with ASD or not. In single parent households, having a child with ASD resulted in 2.115 times greater likelihood of utilizing the SNAP benefit than a two parent household without a child with ASD. Single parents without a child with ASD had a 1.715 greater likelihood of using SNAP than the reference group. Black and Other families were much more likely to utilize the SNAP benefit than White families. Higher levels of education and home ownership were also related to a lower likelihood of using the SNAP benefit. Having SSI within the previous year resulted in 2.033 greater likelihood of using SNAP.

As with food assistance, families with children with ASD were more likely than the reference group (two parent household with children without an ASD diagnosis) to

utilize rental assistance from federal, state, or local government programs. Being from a single parent household and having a child with ASD resulted in being much more likely to utilize rental assistance. Research has shown that people who utilize low-income rental housing are more likely to be in residences with deferred maintenance, higher tenant turnover, and are more exposed to the risks associated with poor housing quality (for example, unintentional injury, respiratory issues) (Lubell, Crain, & Cohen, 2007). While there is a dearth of research on families with children with ASD and housing needs, a longitudinal study following people with Human Immunodeficiency Virus (H.I.V.) over a period of years found that those receiving rental assistance are more likely to enter medical care than those who do not receive assistance. The program found that if people who have housing needs get assistance, they are more likely to follow up with and adhere to treatment regimens (Lubell, Crain, & Cohen, 2007). While a causal link cannot be established, this may have important implications for meeting the needs of children with ASD, who are known to be high users of the medical service system (Lavelle, et al., 2014; Amendah, Grosse, Peacock, & Mandell, 2011).

Being in a one parent household, with children with or without an ASD diagnosis, resulted in being twice as likely to utilize public health assistance, such as Medicaid or SCHIP, than two parent households with children without an ASD diagnosis. Two parent households with a child with ASD were also more likely than the reference group to use public health insurance, though less so. Public health benefits are an important source of insurance for children with ASD.

Implications for policy, practice, and research

Policy implications. The role of the social safety net is important for people with disabilities and their families. Overall, this study suggests public benefits are successfully reaching this population. However, it is also known that people remain vulnerable and with unmet needs while accessing supports. While prior research has suggested that families with children with ASD are more economically-advantaged, results from this study show otherwise. Further, when differences have been shown in past research, there are convincing arguments that they are due to issues of knowledge, access, and resources rather than a true difference. As the rates of family structures more vulnerable to economic hardship rise (such as single mothers) (Kalil & Ryan, 2010), the importance of the public safety net for families who have children with ASD becomes clear.

Programs which alleviate food insecurity, such as SNAP, are essential to alleviating hardship. Previous research well-establishes the significant impact of SNAP in reducing food insecurity (Ratcliffe, McKernan, & Zhang, 2011) (Gundersen & Ziliak, 2015) (Nord & Golla, 2009). Food insecurity is connected with an array of negative outcomes, including poor health among children (including asthma, iron deficiency, and tooth decay), lower academic achievement, and depression and anxiety (in both mothers and children), (Gundersen & Ziliak, 2015). Yet, many people remain food insecure, even on SNAP. These results found that families that have children with ASD are more likely to access SNAP than families with children without the diagnosis. It may be particularly important for policymakers to understand needs related to meeting food security in these

households and to determine if eligibility requirements and outreach, for example, are making this important benefit accessible.

Previous research has shown that children with ASD have higher levels of health care office visits and prescription drug use (Lavelle, et al., 2014), more nonemergency outpatient and emergency department visits (Amendah, Grosse, Peacock, & Mandell, 2011; Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Gurney, McPheeters, & Davis, 2006) than their typically developing peers. In addition to utilization of these services, children with ASD often access therapeutic medical interventions. Adherence to treatment is found to be positively associated with stable housing (Lubell, Crain, & Cohen, 2007), and in the case of ASD, where the time-intensive therapeutic intervention of ABA is the gold standard, this may be particularly important. Additionally, past research has indicated that children receiving Medicaid or SCHIP are less likely to have problems accessing preventative care and prescription medications than their peers with private insurance; poverty and race were shown to increase problems with accessing a specialist (Liptak, et al., 2008).

Medicaid and SCHIP provide coverage to over 72.5 million American, including children, pregnant women, parents, seniors, and individuals with disabilities; Medicaid is the largest source of health coverage in the United States (Centers for Medicare & Medicaid Services, 2016). In terms of policy, it is clear that programs which support meeting the housing and medical needs of families with children with ASD are important to the family functioning, and the theoretical frameworks upon which this study is rested also support and recognize the importance of these factors for building capacity in families. To help eliminate disparities, and so all children may see the benefits of early

intervention, it is suggested that universal screening for children for autism, as well as programs targeting underserved groups of children, families, and health care providers may be important in eliminating disparities in access to care and early intervention (Liptak, et al., 2008). Further, and as discussed in more detail below in the section on implications for practice, as families with children with ASD spend considerable amount of time per week coordinating care (Kogan, et al., 2008), this research supports the importance of policies aimed at promoting medical home models of care in terms of increasing the resources (financial or other) a family can draw upon to reduce stress.

Research implications. Research in autism spectrum disorder has tended to use overwhelmingly White, middle to upper middle class samples, and has often excluded children with multiple disabilities and/or severe to profound intellectual disabilities (Lord & Bishop, 2010). Research aimed at understanding the heterogeneity of ASD is needed, and this includes expanding the sample populations participating in research. A challenge to this remains ascertainment bias.

Conducting longitudinal studies following families with children with ASD over time would contribute understanding of family characteristics, and conducting these in subpopulations to specifically understand experiences of diverse groups would assist in contributing a fuller understanding of ASDs effects on families beyond the White, upper class. Doing this work, as well as prevalence work, may also serve to dispel perceptions of ASD as a White, upper middle class family experience.

Parents who have a child with ASD have a 2% to 18% chance of having another child with ASD (Ozonoff, et al., 2011; Sumi, Taniai, Miyachi, & Tanemura, 2006). Research which explores the impact of this on families is warranted.

It would be useful to conduct prevalence estimates on families over time, as monitoring for changes using the same methods over time makes these estimates most useful. Of note, the 2011-2013 prevalence rate using NHIS data was 1.25% (Zablotsky, et al, 2015). This was prior to the change in wording around the autism question on the NHIS, emphasizing the importance in determining prevalence using the same methods over time. Outreach in under-represented populations is particularly important. By getting services to children from under-represented populations (lower SES, minority), health disparities related to ASD may diminish over time as these groups begin to recognize the benefits of early intervention.

There is a lack of research using large, nationally-representative datasets to understand family structures of children with ASD as compared to those without children without ASD. Findings differ between the studies which have been completed, including this one. Additional research on this issue is warranted to better understand the likelihood and impact of children with ASD existing in different family structures. Further, including geographical location may reveal further differences and insights in to the families and communities impacted by ASD, offering critical information to the service systems in these locales.

Research suggests that ASD co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses in 83% of children (Centers for Disease Control and Prevention, 2016). The factors associated with public benefit usage (low income, less educated, and so on) are also factors which make a person more vulnerable to depression and anxiety. Given the large percentage of co-morbidity in conditions, future research should explore these intersections. Future research on ASD using NHIS

will have the benefit of additional years of data which will allow for investigations in to more granular topics, in particular looking at different disability categories, such as intellectual and developmental disability, and the effects on families with children with ASD.

Broadening understandings of public benefit usage and policy implications through expanding research to look at additional factors and programs impacting the population may be useful.

In addition to research utilizing quantitative methods and exploring large datasets, these findings indicate the importance of conducting qualitative research to understand family experiences. Of particular importance is qualitative research aimed at understanding how families across different structures engage with public benefits and service systems.

Practice implications. This study identifies family structures of children with ASD, finding these children are more likely to reside in single mother households and less likely to reside in two-parent households than children without an ASD diagnosis. In the preamble to the Code of Ethics, the National Association of Social Workers (NASW) states as the primary mission "…empowerment of people who are vulnerable, oppressed, and living in poverty" (National Association of Social Workers, 2008). In particular, this study offers insights in to the resources which may shore up a family's resiliency, including public benefits, and thus highlighting the important role for social workers in advocating for strengthened policy around public benefit access and eligibility. This is in line with the NASW value of social justice, and the subsequent ethical principle which

calls on social workers to engage in change efforts around access to resources, among other things.

NASW also identifies recognizing the dignity and worth of the person, and the importance of human relationships as core values. Within the ethical principles of these values is the recognition that there is capacity for change, for adaptation. The role of the social worker is to honor and promote capacity for change and to seek to strengthen of the family as an important conduit for change (National Association of Social Workers, 2008).

This study draws on theoretical frameworks which recognize resources as vital to resiliency, capacity for resiliency, and positive adaptation for families. In identifying family structures and associations with factors known to be important resources to a family with a child with ASD, the importance of employing a strengths-based approach is highlighted. Helping families to recognize and build on assets may encourage continued positive adjustment. Instead of focusing on deficits, a social worker using a strengths-based approach will spend little time focusing on problems. Rather, the practice will focus on identifying and uncovering strengths aimed at asset building. This is strongly related to resilience-based practice with the shared focus on reducing risks and building protective factors—a strengths-based approach promotes resiliency in families (Early & GlenMaye, 2000) (Fraser, Galinsky, & Richman, 1999). The findings from this study reveal differences in the experiences among family structures for families with children with ASD, and offer insights in to different SES factors and public benefits usage may be attended to by practitioners seeking to support these families.

Family centered care and utilizing a medical home model are also areas of practice supported by the findings of this research. The theoretical frameworks describe the importance of building family resiliency and resources in order to adapt, and to recognize the family as capable. Likewise, family centered care approaches are grounded in mutually beneficial relationships in service planning and delivery where families are placed in decision-making roles. Promoting family members knowledge and agency is a vital part of this process. Similarly, a medical home model describes care that is comprehensive and coordinated. Both models of care, supported by the theoretical frameworks this study draws upon, may increase parenting confidence and confidence, critical aspects of a family adapting positively to their child's disability (Dunst & Dempsey, 2007). When a family does not have to spend time on managing multiple disconnected services for their child, they are left with more time, a resource itself, as well as opportunity to build other resources, including participation on the workforce. These approaches to care may be very empowering for families of children with disabilities (Dempsey & Dunst, 2004). While family-centered care and the medical home model may sound costly, up front costs are likely recouped by the reduction in duplication of services and reduced medical visits

Limitations

There are many advantages to utilizing NHIS data. It is a nationally representative sample of the non-institutionalized population of the United States, allowing for accurate estimates of self-reported conditions, disease, and healthcare utilization over time. Prevalence estimates are improved by over-sampling under-represented minority populations, and in this version of NHIS, over-sampling at the

household level was not done. The health data are self-reported and therefore subject to bias and error. In terms of ASD specifically, only those families who have received a diagnosis will be accounted for (this is further complicated by the myriad of issues that are associated with obtaining a diagnosis of ASD).

Overall, having a large dataset is an advantage and in this study, nearly 500 cases of children with ASD were identified. However, the large dataset may have increased the likelihood of uncovering differences that were significant from a statistical, but not practical, perspective. Additionally, cross-sectional designs are challenged in studying rare diseases. ASD is a low incidence disability, and this study attempts to address that by pooling 2014 and 2015 data in order to have enough subjects to statistically test hypotheses.

There are inherent limitations within the design of the study, and the source data survey. While offering valuable insight in to the relationships between variables, the study cannot determine why such relationships exist. It is not possible to establish temporal relationships, making causality impossible to determine. An important additional limitation is the reliance on self-reported information, and in the case of data on the child, reporting by a proxy.

Low N on sub-populations prevent a more granular look at family structures. As more data is accumulated, there will be more data to pool, making these investigations possible. Likewise, the income measures available in the public-use NHIS files are broad in nature, reducing the ability to examine differences in income in fine detail.

In terms of public benefit usage, in order to receive certain public benefits, such as SSI, one must be a citizen of the United States. NHIS, however, surveys both citizens and non-citizens, and this is unable to be distinguished in the data. Additionally, some research suggests benefit-usage may be under-reported in NHIS.

In terms of socioeconomic status, in addition to education and income, occupation is often also considered in research. Data on occupation is not publicly available in the NHIS public release dataset.

Finally, as has been discussed, ASD is itself a complex condition, and has recently undergone a diagnostic update. The data on families with children with ASD included in NHIS surrounding the Sample Child autism question are subject to the same limitations found in much of the research on ASD, including ascertainment bias.

Conclusion

Families that have children with ASD are having different experiences than families without children with ASD around a number of important indicators of socioeconomic status. This study drew from theoretical frameworks which describe the ways that factors associated with resiliency, resources (both personal and financial), and perception, are vital to the family experience. Past research has explored the ways these impact families with children with ASD, affirming the theory by suggesting that rather than severity of diagnosis, it is resources and assistance with stressors that build resiliency, help with perceptions, and impact a family's positive adaptation to the reality of having a child with autism in the family. The relationships between social supports,

family functioning, and stress are well established. This study contributes to the body of knowledge on families with children with ASD by parsing out their experiences and outcomes in relation to SES factors that align with building resiliency and resources. While no temporal relationships nor causation can be established by this study, important associations between SES factors and family experiences are observed, providing insight in to how well-equipped families with children with ASD may be for supporting their child and their family, as well as providing directions for future research, policy, and service systems to explore.

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Appendix A. NHIS Variables with coding type and description

Name	NHIS Label	Coding/Response options
ASD status	AUTISMEV	Family member was told that child has ASD.
Family arrangement	FAMSTRUC1F	Family structure according to familial relationship status and parental marital status if children are present.
Mother education level	MOMED	For all persons under age 18, reports the person's mother's education in intervalled groups.
Father education level	DADED	For all persons under age 18, reports the person's father's education in intervalled groups.
Race	RACEA	Incorporates information from RACEID and RACESR; the self-reported, main racial background of all persons using the pre-1997 Office of Management and Budget's (OMB's) Statistical Policy Directive No. 15 (Race and Ethnic Standards for Federal Statistics and Administrative Reporting)
Hispanic	HISPETH	Identifies and classifies persons of Hispanic/Spanish/Latino origin or ancestry
Poverty level	POORYN	Indicates whether family income was above or below the poverty level
Family income	INCFAM07ON	Provides total grouped family income
SSI benefit	GOTSSI	Received income from SSI
Food assistance recipient	GOTSTAMPFAM	Any family member authorized to receive food stamps or SNAP benefits during month prior to interview or during the previous calendar year
Housing	OWNERSHIP	Whether home is owned or rented or other

Rental assistance	LOWRENT	If family pays lower rent because federal, state, or local government was paying part of the cost
Public Health Insurance	HIPUBCOVE	Has any Medicaid/other public assistance/State sponsored plan or CHIP